Abstracts of the 7th World Research Congress of the European Association for Palliative Care (EAPC)

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Abstracts

Plenary session I

Abstract number: INV1
Abstract type: Invited Speaker

The Development of a Research Field Over 25 Years: Most Important Findings and Their Impact

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Palliative care emerged as a response to the unmet needs of patients and families receiving main stream medical care. Most clinical programs developed outside major academic centers and the adoption of palliative care and later palliative medicine into main stream academic medicine has been slow in most of the world. As a result, the development of a research field has been slow and considerably under funded. Even with those limitations, palliative care has generated the evidence that dramatically changed the care of patients and their families facing progressively incurable diseases. This presentation will review major research improvements in the area of the assessment of symptoms, delirium and chemical coping, the development of regular opioid analgesia, the recognition and successful management of opioid induced neurotoxicity, the adoption of the subcutaneous route, improvements in the assessment and management of dyspnea, fatigue, delirium, and communication. Finally, this presentation will address the results of outcomes research on important settings such as the palliative care unit and the outpatient supportive and palliative care centers.

This presentation will conclude by proposing important areas where future research should be conducted.

Abstract number: PL1
Abstract type: Plenary

Interventions for Fatigue and Weight Loss in Adults with Advanced Progressive Illness: A Cochrane Overview of Systematic Reviews

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Aims: To conduct an overview of the evidence available on the efficacy of interventions used in the management of fatigue and/or unintentional weight loss in adults with advanced progressive illness by reviewing the evidence contained within Cochrane reviews.

Methods: The Cochrane Database of Systematic Reviews (CDSR) was searched for all systematic reviews evaluating any interventions for the management of fatigue and/or unintentional weight loss in adults with advanced progressive illness (Issue 8, 2010). Titles of interest were reviewed by abstract. Where the relevance of a review remained unclear a consensus was reached regarding the relevance of the participant group and the outcome measures to the overview. The data was extracted independently by two overview authors using a data extraction form. The measurement tool AMSTAR (Assessment of Multiple SysTemAtic Reviews) was used to assess the methodological quality of each systematic review.

Results: Twenty-seven systematic reviews (302 studies with 31833 participants) were included in the review. None of the included systematic reviews reported quantitative data on the efficacy of interventions to manage fatigue or weight loss specific to people with advanced progressive illness. All of the included reviews apart from one were deemed of high methodological quality.

Conclusion: There is a lack of robust evidence for interventions to manage fatigue and/or unintentional weight loss in the advanced stage of progressive illnesses. The evidence contained within this overview provides some insight into interventions which may prove of benefit within this population such as exercise, some pharmacological treatments and support for self-management. There is a need for standardised reporting of these symptoms and agreement amongst researchers on the minimum duration of studies and minimum percentage change in symptom experience that proves the benefits of an intervention.
Spiritual Care in Palliative Home Care. A Qualitative Study Using the Nominal Group Technique and the Delphi Technique

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Background: Most patients with advanced progressive disease prefer to receive end-of-life care and to die at home, if adequate support is available. Spiritual care at the end of life remains poorly understood despite its promotion by the World Health Organisation.

Aim: To develop a consensus-based set of relevant elements of spiritual care in palliative home care.

Methods: Expert meeting with nominal group technique (NGT), followed by a two stage web-based Delphi technique using an online rating process to enable international collaboration. Experts from three stakeholder groups (physicians, professional spiritual caregivers and researchers) representing two countries (Belgium and the Netherlands) listed elements of spiritual care in palliative home care by means of the NGT. Using the NGT results, a Delphi process was performed with the same experts to check their agreement with the highest ranked elements of spiritual care. Participants were asked to rate the relevance of the elements on a scale from 1=not relevant to 9=very relevant. Raters could also choose to add free text comments. In the second round we presented raters with the (anonymous) written comments from the first round.

Results: This study has yielded nine domains with 14 relevant elements of spiritual care in palliative home care:

1) end-of-life expectations and wishes,
2) rituals,
3) stories,
4) inner resources,
5) making contact,
6) creating a safe environment,
7) integration in biopsychosocial care,
8) care for the caregiver and
9) interdisciplinary team.

Conclusions: Physicians, professional spiritual caregivers and researchers agreed on 14 relevant elements of spiritual care in palliative home care. There were no differences between the three stakeholder groups. This study provides an important first step towards the development of an interdisciplinary model of spiritual care in palliative home care. Further research is needed to operationalise it in daily practice.

A Randomised Controlled Trial of Oral Morphine versus Oral Oxycodone for the Treatment of Pain in Cancer Patients

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Introduction: The inter-individual variation in response to opioids is recognised and the therapeutic benefit of opioid switching is established but few RCT’s define the clinical characteristics of these phenomena. The aim of this study was to compare the clinical response of morphine (M) and oxycodone (O) when used as first-line strong opioid and after switching from one to the other (second line).

Methods: 200 opioid naïve cancer patients, commencing regular WHO Step 3 opioids were randomised to receive either oral M or O as first-line therapy. Opioid dose was titrated to clinical response. Patients who did not respond were switched to the alternative opioid (switchers). Pain was monitored using the modified BPI and side-effects using a NRS (0-10). Primary outcome was defined as clinical response to first-line opioid (adequate pain control with acceptable side-effects). Patients were followed for 1 year.

Results: 100 patients were randomised to each arm, age 59.1 ±12.6 years, 89% Caucasian. Median (range) survival from study entry was 91days (3-1160). Median time to reach “clinical response” was 7 days for both M and O. Intention to treat analysis shows no significant difference in first-line clinical response rates to M vs O; (61/98) vs(67/100) respectively (X^2 = 0.49, p=0.48) or second line opioid in the ‘switchers’; (17/29) who switched to O, compared with 11/17 who switched to M. Subgroup analysis identified (a) Early switchers occurred after a median time of 7 days for both opioids (b)Late switchers for M responders 125 days (range 35-169) and for O responders 30 days (6-129). No difference in frequency or severity of reported adverse reactions between M and O. Opioid switching was most often due to drowsiness followed by uncontrolled pain, nausea and confusion/hallucinations/disorientation.

Conclusions: Response to M or O, first or second line, was not significantly different. Opioid switching, substituting M to O or vice versa, improves outcomes.
Cancer cachexia

Abstract number: INV2
Abstract type: Invited Speaker

Definition and Classification of Cancer Cachexia

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Cancer cachexia is defined as 'a multi-factorial syndrome defined by an ongoing loss of skeletal muscle mass (with or without loss of fat mass) that cannot be fully reversed by conventional nutritional support and leads to progressive functional impairment. Its pathophysiology is characterized by a negative protein and energy balance driven by a variable combination of reduced food intake and abnormal metabolism'. The agreed diagnostic criterion for cachexia are weight loss >5%, or weight loss >2% in individuals already showing depletion according to current body weight and height (BMI < 20 kg/m²) or skeletal muscle mass (sarcopenia). It is agreed that the cachexia syndrome can develop progressively through various stages - pre-cachexia to cachexia to refractory cachexia. Severity can be classified according to degree of depletion of energy stores and body protein (BMI) in combination with degree of ongoing weight-loss. Assessment for classification and clinical management should include the following domains: ‘anorexia/reduced food intake, catabolic drive, muscle mass and strength, functional and psychosocial impairment’.

Consensus exists on a framework for the definition and classification of cancer cachexia. After validation, this should aid clinical trial design, the development of practice guidelines and eventually routine clinical management.

Abstract number: INV3
Abstract type: Invited Speaker

The Evidence for Nutritional Support in Multimodal Therapy for Cancer Cachexia

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Cancer cachexia has been defined as a multifactorial syndrome characterised by an ongoing loss of skeletal muscle, with or without loss of fat mass, that cannot be fully reversed by conventional nutritional support and leads to progressive functional impairment. It reflects a journey along two parallel pathways: 1/A catabolic metabolism, mainly as a systemic inflammatory response, and 2/ A negative energy balance driven by a combination of reduced food intake and sometimes increased resting energy expenditure.

Nutritional support alone can improve energy intake to a variable extent and maintain or increase body energy stores, but is unable to reverse muscle catabolism, which appears not to be nutritionally regulated. Thus, nutritional support alone is of limited efficacy without targeting the catabolic response. Such therapy could, in principle, be directed towards the tumour itself, the inflammatory response or the catabolic metabolism. Nutritional support in cancer cachexia should thus be evaluated in a multimodal context, taking into account effects of other treatment modalities.

Increased intake alone was shown many years ago to be ineffective to prolong survival. However, when combined with either anti-inflammatory treatment, or palliative chemotherapy, function, quality of life, and survival tends to improve. Similarly, oral nutritional support has been shown to improve outcomes in cancer patients undergoing radiotherapy.

The evidence is still quite limited, and there is currently no single or combined treatment strategy which successful in all patients. However, strategies to counteract both catabolism and reduced dietary intake have been demonstrated to be of importance for outcome and should be further explored in interventional studies.

Thus, improved management of cancer cachexia may require a multimodal approach by a multi-disciplinary team and is best commenced earlier rather than later.

Abstract number: INV4
Abstract type: Invited Speaker

Pathophysiology of cachexia. Common features in cancer and COPD?

Schols, A.

Education and information

Abstract number: OA1
Abstract type: Oral

Development and Preliminary Assessment of a School-based Intervention on Palliative Care. (Phase 0-2 MRC Framework)

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Aims: Developing and preliminarily testing an educational package on palliative care addressed to high school students.

Study population: 5 classes of 5 high schools in Genoa.

Design and methods: Development and evaluation of package was conducted using the Medical Research Council (MRC) Framework for the Evaluation of Complex Interventions. The project is divided into:
1) screening of the film “La prima cosa bella” (Virzi P, 2010) and discussion with students on palliative care;
2) a meeting per class aimed at eliciting students’ point of view on palliative care, with a clinical psychologist expert on palliative care and a hospice nurse;
3) a multimedia product on the theme of “Severe illness and strategies to deal with it” realised by the 5 classes;
4) a preliminary evaluation of the procedures and impact of the intervention on students and teachers (before-after evaluation).

Statistical analysis: Descriptive and content analysis of the questionnaires; comparisons between the students answers through paired McNemar Tests.

Results: Valid questionnaires were filled in by 84% and 79% of the students in the before-after evaluation. 40% of respondents had heard of palliative care: from media (57%), from school (57%) and from family (33%). A correct definition of palliative care has been done by about 30% of the students in the before evaluation and by more than 90% in the after evaluation. The experience has been evaluated by the students as: “interesting” (83%), “useful” (57%) and “enriching” (41%). Only 4% of the students has evaluated this experience as “boring”. The content analysis of the qualitative sections of the questionnaires is in progress.

Conclusions: Our findings suggest that this package might improve attitudes and knowledge of high school students on palliative care. However, before being proposed at a regional or national scale, the package has to be evaluated in a larger sample. This work was supported by Liguria Region.

Abstract number: OA2
Abstract type: Oral
Teaching Interprofessional Palliative Care Competencies with Practice Based Small Group Learning (PBSG) Modules: Their Use for Physicians in Practice and Postgraduates in Training

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Aims: Problem Based small group learning is accepted as a robust, successful and popular method of adult learning for physicians in clinical practice. In Canada, the Foundation for Medical Practice Education has been producing standardized PBSG modules on various areas of clinical practice, for over 20 years. In recent years, at the request of Canadian physicians, several modules have been created that address key topics in Palliative/End of Life care. These modules are also excellent for postgraduate programs to use to help physicians in training achieve many of the expected competencies in Palliative Care. In this workshop, the PBSG format, Palliative Care content and competencies and how these Palliative care modules look and run, will be explained and experienced.

Methods: Intended outcomes
1. Participants will learn about this the PBSG program, format and adult learning theory.
2. Participants will learn about the palliative/end of life care modules and which national (Canadian) competencies in palliative care for postgraduate physician trainees, that they meet.
3. Participants will understand how a PBSG group work and how the modules work.

Results/conclusions: This workshop will introduce the concepts of PBSG modules and the palliative care modules and competencies, in a discussion with the entire group. Then participants will be divided into groups of 6-8 to experience one of the Palliative Care modules.

Abstract number: OA3
Abstract type: Oral
Palliative Care in Undergraduate Medical Education in Munich, Germany

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Aims: The study was designed to examine students’ and educators’ self-assessment regarding their attitudes, skills and knowledge towards palliative care and to map out the deficiencies of palliative care seminars in order to improve the content and achieve better outcomes.

Methods: The students were asked to fill out the demographic data and evaluate their general expertise in palliative care. Additionally, they self-assessed their individual attitudes, skills and knowledge using numerical rating scales ranging from zero to ten (T1, T2, T3). A similar evaluation sheet was filled out by educators (T3).

Statistical analysis software (SPSS) was used to analyze and describe the data collected. The feedback (open comments) from students was integrated into the study to make the possible problems even more explicit.

Results: The general evaluation of palliative care seminars demonstrated that 93% of the students found the course well organized and the educators competent. According to the students’ evaluation the most important aspect in the non-medical palliative care is the grief management followed by the principles of palliative care and psychosocial care. Considering the importance of spiritual care the students were more reserved. The evaluation of students’ individual attitudes, skills and knowledge showed constant improvement in all aspects of palliative care. Regarding the question “if the studied content has a practical value in the work life” the respondents’ answers were mostly positive.
Conclusions: The majority of students would like to gain a solid in-depth knowledge in palliative care, at the same time doubting if such skills can be learned during plain lectures even if these include discussions and role plays. The EAPC recommends 40 hours of palliative education for medical undergraduates with additional clinical rotations. Considering the amount of students (220 students per semester) the target of EAPC is difficult to achieve.

Abstract number: OA4
Abstract type: Oral

The Family Approach to Weight and Eating (FAWE): An Investigation of the Acceptability, Feasibility and Perceived Effect of a New Psycho-educational Intervention for Cancer Cachexia-related Distress

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Aims: Up to 80% of people with cancer experience involuntary weight loss and eating problems. These symptoms of cancer cachexia can cause distress in patients and their family carers. The Macmillan Weight and Eating Studies (2000-11) have developed the first psycho-educational intervention for families affected by cachexia-related distress: The Family Approach to Weight and Eating (FAWE). The aim of this paper is to report an investigation of the acceptability, feasibility and perceived effect of FAWE.

Methods: The Phase I study of FAWE (as defined by the Medical Research Council’s guidelines for developing a complex intervention) was conducted in 2010-11 and recruited a purposive sample of 20 patient-family carer dyads affected by cancer cachexia in the UK. It was a mixed-methods cross-sectional feasibility study to investigate i) the deliverability of FAWE, ii) it’s acceptability, iii) perceived benefits and potential harms, and iv) the feasibility of a follow-on Phase II trial. Analysis included the use of descriptive statistics, framework analysis of the qualitative data, and critical review by the study Expert User Involvement Group. The FAWE intervention was refined through the analytic process.

Results: FAWE was tested with 16/20 dyads, where the patients were of age range 41-84 and seven were female. Measures included eating-related distress (ERD) using a visual analogue scale with zero being no distress. Prior to intervention patient ERD ranged 0-8.5 (median 1.5) and family carer ERD ranged 0.5-10 (median 6.5). Dyads valued the information that they were given about cancer cachexia and how to eat well whilst living with the syndrome. FAWE was observed to facilitate the desired family talk about food, feelings and reciprocity, without adverse consequences.

Conclusion: FAWE is acceptable, deliverable and perceived by patient-family carer dyads to be of benefit. It now needs testing in a Phase II trial.

Funder: Macmillan Cancer Support

Abstract number: OA5
Abstract type: Oral

Readability of Informed Consent Documents (ICDs) in Clinical Trials (1987-2007) - A Linguistic Approach

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Aims: The goal of an informed consent document (ICD) is to ask the reader to participate in research, and to explain the implications of being a research participant. An ICD is readable if it is written according to this overall goal. The aim of this study was to investigate the readability of ICDs linguistically and to compare old and new ICDs in this respect.

Methods: Twenty ICDs (ten from the 1980s (“old ICDs”) and ten from 2006-2007 (“new ICDs”)) were included. The Evaluative Linguistic Framework (ELF) was used to analyse the texts with a focus on main themes, order of themes, rhetorical functions, the relationship between reader and writer, metadiscourse, headings, expert terminology, and visual aspects.

Results: Several textual aspects contribute to increasing or decreasing ICDs’ readability. The new ICDs were found to be more readable than the old ones because they were more oriented towards research, both in the main heading, by placing the request to participate in the beginning, and thematically throughout the entire document. Also increasing readability in the new ICDs were instructions about how to consent, and clear contact information. Aspects that might reduce readability in new ICDs were the large number of topics, details and actors. The readability of the old ICDs was enhanced by fewer topics, a clear presentation of the involved actors, and brevity. However, the old ICDs’ readability may have been reduced by too much information about the reader’s diagnosis and treatment, and less orientation towards the research project.
Conclusion: New ICDs were as readable as old ICDs according to the textual characteristics identified in this document analysis. Two main aspects contributing to readable ICDs is a clear focus on the topic of research and a clear presentation of the actors, including who will perform which actions subsequent the reading of the ICD.

Abstract number: OA6
Abstract type: Oral

Older Patients’ Experiences of Patient-physician End-of-Life Communication: Evidence from the United Kingdom, Belgium and the Netherlands

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Aims: Older patients often experience sub-standard communication in end-of-life care. Due to the importance of good communication in patient-centred end-of-life care, it is essential to understand the factors which influence older patients’ communication with physicians. This study examines older patients’ experiences of patient-physician end-of-life communication in three northern European countries.

Study population: A purposive sub-sample of interviews from British, Dutch and Belgian studies on patients’ attitudes to death, dying and end-of-life care. Qualitative interviews with patients over 60 were selected.

Design and methods: A secondary analysis: cross-cutting themes were identified using a constant comparison approach.

Results: Themes from 40 interviews (Male 63%, Cancer 58%) included: perception of the physician’s role; disclosure; confidence and trust; and participation. Incongruence between the WHO defined scope of palliative care and what some patients considered appropriate for discussion with their physician was identified. Trust and confidence were reinforced by physicians’ availability, time, and genuine attention and hindered by misdiagnoses and poor communication style. Most patients preferred full disclosure, though some remained deliberately ill-informed to avoid distress. Many patients were actively involved in treatment decisions; some involved family members, whereas others were not involved. There were a few complaints that only information about physician’s preferred treatment was given.

Conclusion: The findings reveal barriers to idealised notions of informed consent and patient-centred decision-making anticipated by the dominant informed decision-making model. This model assumes patients make rational choices, free from coercion, based on a clear understanding of treatment options. The interviews of older patients from three northern European countries, however, demonstrate that this idealised situation often does not occur in practice.

Palliative care for children and older people

Abstract number: OA7
Abstract type: Oral

Symptom Profiles in Children with Advanced Cancer Attending an Outpatient Oncology Clinic: Child and Family Caregiver Ratings

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Aims: 1. To characterize symptom (sx) profiles of children with advanced cancer attending an outpatient pediatric oncology clinic
2.To evaluate frequency of agreement of proxy raters for presence/absence of sx.

Methods: The pediatric Memorial Symptom Assessment Scale (pMSAS) is a validated tool that evaluates 8 sx (version 7-12) or 30 sx (version 10-18) for children in the corresponding age range. The pMSAS was translated into neutral Spanish (S) language versions. Children ages 7-10 years were administered the pMSAS 7-12 and ages 11-18 years, the pMSAS 10-18 in English (E) or S just prior to their physician (MD) visit. Family caregivers (fCG) were independently administered the corresponding pMSAS version. Analysis was descriptive, with frequency of agreement regarding presence or absence of sx (95% confidence limit [CI]) determined using the child as the gold standard.

Results: 60 children [mean age (±SD) 12 (±4), 62% male, 35 S] and their fCG completed the age appropriate version
of the pMSAS. 30 children completed the pMSAS 7-12 (mean age ±SD) 9 years (±1), 43% female, 25 E]. Number of symptoms reported was 0 (N=8, 27%), 1 (N=9, 30%) and ≥2 (N=13, 43%). The 3 most common symptoms were “tired” (N=12, 40%), “itchy” (N=9, 30%) and appetite (N=6, 21%). 30 children-fCG dyads completed the pMSAS 10-18 (15 E, 15 S). Patients (pts) were mean age (±SD) 15 years (±3) and 50% female (N=15). Number of symptoms reported was 0 (N=1, 3%), 1 (N=4, 13%) and ≥2 (N=25, 84%). The 3 most common symptoms were “pain” (N=15, 50%), “energy” (N=13, 45%) and “numbness” (N=13, 43%). For pMSAS 7-12, chld/fCG agreement ranged from 63% (95% CI 46-80) for “itchy” to 80% (66-94) for “pain”. Corresponding numbers for pMSAS 10-18 were 43% (26-61) for “worry” to 97% (90-100) for “problems with urination”.

Conclusion: Systematic symptom assessment in children receiving outpatient treatment for cancer and their fCGs is feasible and highly informative. Difference in pt-fCG sx reports are common.

Abstract number: OA8
Abstract type: Oral

Determinants of Death in an Acute Care Hospital for Taiwanese Pediatric Cancer Decedents, 2001-2006

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Objective: To comprehensively disentangle the determinants of place of death for pediatric cancer patients in an unbiased population.

Patients and methods: Retrospective cohort study using administrative data among 1,208 Taiwanese pediatric cancer patients who died in 2001-2006. Place of death was hypothesized to be associated with:
- patient demographics and disease characteristics,
- primary physician’s specialty,
- characteristics and healthcare resources at both the hospital and regional levels, and
- historical trends.

Results: Most Taiwanese pediatric cancer patients (78.8%) died in an acute care hospital. The proportions of hospital death did not change significantly over time, except for a significant increase in 2005 (adjusted odds ratio [AOR], 95% confidence interval [CI]: 1.66 [0.99-2.76]). Taiwanese children had a greater propensity to die in an acute care hospital if they were diagnosed with a hematological malignancy (AOR [95% CI]: 1.61 [1.10-2.38]) and received care in a large hospital (AOR [95% CI]: 1.96 [1.00-3.88] and 1.94 [0.98-3.84] for quartiles 1-3 and >quartile 3, respectively). In contrast, children were less likely to die in a hospital if they had hepatoma (AOR [95% CI]: 0.55[0.33-0.91]).

Conclusion: Taiwanese pediatric cancer patients predominantly died in an acute care hospital with no trend in place of death shifting from hospital to home. Propensity for hospital death was determined by diagnosis and healthcare resources of the primary hospital. Clinical interventions and health policies should ensure resources to be allocated to let pediatric cancer patients die in the place they and their parents prefer to achieve a good death.
Conclusions: Whilst recognising the limitations of the study, it is clear that there is a need for scaling up CPC training around the world. The need for individuals to be trained in CPC throughout the world is great, and ways need to be found to increase access to appropriate and affordable training, internationally, on CPC. Funded by OSI.

Abstract number: OA10
Abstract type: Oral

End of Life Care and Preferred Place of Death for the over 80s: Results from a VOICES Post-bereavement Survey

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Aims: Access to good quality end of life care (EOLC) may be reduced for the oldest old. We aimed to compare EOLC in those over 80 with those under 80 years.

Methods: The Office for National Statistics drew a stratified sample of deaths registered in two English health districts between October 2009 and April 2010. The VOICES questionnaire was sent to each informant (n=1422, usually bereaved relative) 6 to 12 months after the death.

Results: 473 responded (33%), 62% of decedents were aged 80 or over. Over 80s were less likely to be reported to have expressed a preference about place of death (OR=0.52), or have a record of place of death preferences (OR=0.21) than under 80s. This may partly explain why hospital was the most common place of death for those over 80 and they were less likely to have died at home (OR=0.30) or in their reported preferred place (OR=0.35). Moreover, relatives of over 80s were more likely to report treatment decisions which the deceased would not have wanted (OR=2.17). There were no differences in reported quality of care or symptom management based on age. However, cause of death played a role in experiences: relatives of older people who died of cancer (prevalence 19% compared to 57% in under 80s) were less likely report that the deceased died in their preferred place (OR=.232) or had a record of preferred place (OR=.238) than relatives of under 80s with cancer. Indeed, over 80s with cancer were less likely to die at home (OR=.279), and more likely to have died in hospital (OR=.18) than under 80s who died of cancer.

Conclusions: Relatives of the over 80s reported similar EOLC experiences for quality of services, symptom management and respectful treatment compared to relatives of under 80s. However, reports suggest that age-associated disparity exists in the recording and realisation of EOLC preferences. Older people dying of cancer seem to be particularly disadvantaged in EOLC preferences compared to their younger counterparts.

Abstract number: OA11
Abstract type: Oral

Developing a Typology of Dying for Residents in Nursing Care Homes

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Research aim: Symptom assessment is a challenging but essential prelude to symptom management. In nursing care homes, this is an area which has often been overlooked. This original study aims to characterise the physical symptoms experienced by dying residents in nursing care homes and map the longitudinal symptom changes in the dying resident that occur over a specific period of time.

Methods: A prospective longitudinal study was undertaken in 11 nursing care homes in the UK over a 12 month period between 2009 and 2010. Demographic and symptom data was collected in relation to residents (n=157) corresponding to 12 symptoms commonly experienced over the final few days of life.

Results: The average age of a resident dying in a care home is 84.8 years and spent an average of 111 weeks living in the care home before death. A resident has between 1 and 7 diagnosed illnesses (mean=2.65), with dementia being the most common (45%).

The three most common symptoms are drowsiness, fatigue and anorexia (n = 143, 125 and 107). Spearman correlation analyses were performed on the 12 symptoms to determine the strength of correlation between any 2 of the 12 symptoms. A principal component analysis (PCA) was applied to distinguish which symptoms demonstrated a significant relationship with other symptoms. PCA of symptoms within the various diagnosed illnesses revealed differences in the pattern of symptom clusters. From the analysis of symptom clusters, a typology of dying has been constructed to represent the end of life symptoms and changes experienced by a resident dying in a nursing care home.

Conclusion: The findings will establish a typology of dying through an understanding of population characteristic and longitudinal changes which will inform future symptom management advice and guidelines for residents dying in nursing care homes.

Abstract number: OA12
Abstract type: Oral

The EAPC Taskforce on Palliative Care in Long-term Care Settings for Older People: Mapping Good Practice

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EAPC Taskforce on Palliative Care in Long Term Care Settings for Older People

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**Background and aim:** Many older people living and dying in long term care (LTC) settings are in need of palliative care in some phases of their stay there. A key question is how can palliative care be integrated into the organisational culture of long term care settings? Our aim is to identify and map the different ways of developing palliative care in long term care settings across a number of European countries.

**Methods:** Country leads from 12 European countries (Austria, Belgium, France, Germany, Italy, Netherlands, Norway, Portugal, Sweden, Switzerland, UK) have been identified to act as coordinators of data collection within their countries. The work is supported by meetings at EAPC conferences. Two phases of work have been undertaken. In Phase 1, information about the context of long term care provision in each country has been collected considering the types of LTC settings, the status of LTC providers, funding and regulation. In Phase 2, examples of initiatives being undertaken in each country to develop palliative care provision in each country have been collected using a proforma.

**Results:** The context for LTC provision across Europe is variable. All countries offer care that meets low and high levels of dependency. Providers of care are located in the public, private, and not for profit sectors. Funding is complex and sources draw on state and personal funds. Regulation is national or state led. A typology of interventions has been developed that categorises the initiatives. This addresses a number of levels: Individual (staff, family, resident), Group/Team, Organization, Regional /Networks and National. Examples of initiatives across these levels can be seen across Europe.

**Conclusion:** A range of Initiatives are being undertaken to develop and impact on the provision of palliative care in LTC settings for older people across Europe. A compendium of good practice interventions is being compiled to share these examples more widely.

**Pain I**

**Abstract number:** OA13
**Abstract type:** Oral

Palliative Radiotherapy and Bone Metastases: Practice in Norway 1997-2007; A National Registry Based Study

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**Background:** Change in clinical practice is challenging. It is expected that high level of scientific evidence implemented into guidelines will change clinical practice. Numerous randomised clinical trials have shown that the pain relieving effect of single fraction (SF) radiotherapy (RT) - one day treatment, is similar to multiple fraction (MF) RT - two weeks treatment, for patients with bone metastases.

Our research question was: Is clinical practice changed from MF to SF RT in Norway?

A national registry based study was conducted, including all treatment schedules of palliative RT for bone metastases of 8 Gy x 1 and 3 Gy x 10 delivered to bone in 1997-2007. Binomial regression analyses were used to study whether treatment centre, primary diagnosis, anatomical site, age, sex, and travel distance, were associated with the choice of treatment.

A total of 14380 episodes of RT were identified. In 31% of the treatments, SF RT was used. The proportion of SF RT increased during the study period from 16% in 1997 to 41% in 2007. There were substantial differences in the use of SF RT between the treatment centres, ranging from 25% to 54%, and these differences persisted after adjustment for primary diagnosis, anatomical site, age, sex and travel distance. In most centres, there was a time related increase in the use of SF RT, however, in one centre, there was a decreasing trend.

The results demonstrate that evidence based changes in daily clinical practice are challenging, and that the choice of treatment often is based on past teaching, local traditions and local opinion leaders rather than scientific evidences. Such a conservative approach may limit patients’ opportunity to stay at home during treatment.

The project was funded by the Faculty of Medicine at the Norwegian University of Technology and Science, Trondheim, Norway.

**Abstract number:** OA14
**Abstract type:** Oral

Does Regular Paracetamol Offer Additional Analgesic Benefit for Patients with Cancer Pain Taking Strong Opioids? A Systematic Review
**Aim:** Methoxyflurane is a halogenated inhalational anaesthetic/analgesic. It is self-administered using a Penthrox™ Inhaler and indicated for use in Australia and New Zealand in pre-hospital pain, and in the relief of pain associated with short surgical procedures. This randomized, double-blind, placebo-controlled study assessed the safety and efficacy of methoxyflurane in patients with cancer undergoing a bone marrow biopsy (BMB).

**Methods:** Ninety-seven of 100 randomized patients underwent bone marrow biopsy and received local anesthesia plus either methoxyflurane or placebo with pain intensity measured at 6 time points during the bone marrow biopsy using the Numerical Rating Scale. Patients, operators and research nurses rated global medication performance at the end of the bone marrow biopsy. Other measures included anxiety, side effects, concomitant medications, fluoride levels, number of previous BMBS, sedation use and duration of use of inhaler. Primary outcome measure was worst pain score during BMB based on clinically meaningful improvement of at least 1.5 mean worst pain.

**Results:** The worst pain overall was significantly higher in the placebo arm of the study (5.40 +/- 2.21) than in methoxyflurane arm (4.90 +/- 2.07) (p = 0.011). There was a significant statistical difference in patients’ rating between patients on different arms of study (p=0.005). Medication was globally better rated by patients who received Methoxyflurane. The study nurse rated methoxyflurane significantly better than placebo (p < 0.001) at controlling pain experienced by patients which was in moderate agreement with subject ratings. There were significantly more adverse events with methoxyflurane vs placebo arm (p = 0.028), all were grade 1 (mild) and previously reported. There was no renal toxicity.

**Conclusion:** Self-administered Methoxyflurane via the Penthrox™ inhaler was safe, simple to use, well tolerated and efficacious.

**Abstract number:** OA16

**Abstract type:** Oral

**European Open-label Multicentre Phase IV Study in Patients with Breakthrough Cancer Pain (BTcP) Treated with Fentanyl Buccal Tablet to Evaluate Quality of Life**


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Fentanyl buccal tablet (FBT) is indicated for treating adult patients with BTcP receiving opioid maintenance therapy and should be titrated to a successful dose that provides adequate analgesia with acceptable adverse events. This study had 3 periods: screening, open-label randomized titration [patients titrated FBT starting at 100 or 200 µg up to successful dose (100, 200, 400, 600, 800 µg)], and open-label treatment (of up to 8 BTcP episodes). The patients’ inclusion followed the FBT label. 442 patients were screened and 330 randomised in 135 sites (7 European countries). The primary outcome demonstrates the non-inferiority of the percentage of patients achieving a successful dose by titration starting with 100 µg to that with 200 µg. This study also evaluated the effect of treatment with FBT on patients’ quality of life. Most patients were previously treated for BTcP (93.6%, 309/330). Patients’ quality of life and functional status [modified Brief Pain Inventory-short version 7 item subscale (BPI-7S)] and global assessment [patient satisfaction (8 questions) and ease of use] were assessed. The BTcP interference with the functional status using the BPI-7S indicates an improvement after FBT treatment compared to previous treatment (general activity, mood, walking ability normal work, relation with other people, sleep, enjoyment of life). The mean (SD) BPI global score decreased from 39.6 (15.8) to 31.5 (16.7) after the FBT treatment period [95%CI (-10.5; -6.7)]. Similarly, patient satisfaction improved vs. previous treatment after the treatment period for most questions. At the end of the treatment period, FBT was rated as very easy/convenient and easy/convenient to use by 78.7% (174/221) of patients. Tolerability was as expected for this type of cancer patients with opioid treatments. This open-label study with a large number of patients with BTcP in Europe showed a quality of life improvement when treating BTcP episodes with FBT in real clinical practice.

Abstract number: OA17
Abstract type: Oral

Associations between Plasma Concentrations of Morphine and its Metabolites, Renal Function and Symptoms in Cancer Patients

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Aim: The objective of this study was to analyse the associations between, dose-corrected morphine plasma concentrations and metabolites (M3G and M6G), renal function and the intensity of pain, fatigue, nausea and vomiting in cancer patients.

Methods: This investigation derives from a cross-sectional multicenter study (European Pharmacogenetic Opioid Study (EPOS)), conducted during 2005-2008. Inclusion criteria: malignant disease, age≥18 years and regular scheduled treatment with opioids for moderate or severe cancer pain (≥3 days). 578 patients had available data regarding creatinine and morphine metabolites. Symptoms were assessed through EORTC QLQ - C30 symptom scales ranging from 0 to 100, and the adopted cut-off value was 66.7. Renal function was analysed using the Cockcroft-Gault formula and cut-offs applied were: < 60ml/min impaired renal function and < 30 ml/min severe renal impairment. Multiple logistic regressions adjusted for age, sex and other medications were used to examine the associations.

Results: The patients mean age was 61.9y (SD=12.4) and 52% were men. Logistic regressions showed that patients with higher dose-corrected M6G serum concentrations (P=0.0450) had between 0.75 (95% CI: 0.36-1.58) and 0.49 (95% CI: 0.22-1.10) times lower odds of having nausea and vomiting than patients in the lowest quartile. Odds decreased to 0.27 (95% CI: 0.10-0.69) in the highest quartile. In addition, the analyses indicated that patients with moderate/severe renal impairment were more likely to report nausea and vomiting than patients with normal renal function (P=0.057). No other significant associations were observed.

Conclusion: Higher plasma concentration of M6G was associated with lower frequency of nausea and vomiting and there was also an indication between renal function and nausea and vomiting. Further analyses between renal function, serum levels of other opioids and intensity of different symptoms will be performed.
Abstract number: OA18
Abstract type: Oral

How Important Is Tolerance to Strong Opioids in Terminal Cancer Patients?

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Introduction: The fear for tolerance to opioids is a cause for the under use of strong opioids for cancer pain. Tolerance is a normal physiological response to chronic opioid therapy in which increasing doses are required to result the same pain relief. This study analyzed the strong opioid doses in terminal cancer patients to relief cancer pain of VAS≥4/10.

Patients and methods: The inclusion criteria for analysis were cancer patients, admitted to the palliative care unit (PCU) between 9-1999 and 2-2010, ≥65 y., no longer treatable cancer and who finally died in the PCU. The medical charts of all patients were retrospectively analyzed in detail. Age, gender, primary tumor, metastases at time of admission, pain treatment (dose of opioids/d from >2 months before admission and during the stay in the PCU were registered. The doses of the different strong opioids were recalculated to oral morphine equivalent doses (OME). Patients were stratified based on the max. OME daily dose: < 60 mg/d, 60-299 mg/d, 300-599 mg/d, 600-900 mg/d and > 900 mg/d. The mean OME and standard deviations were calculated for each cohort at various time points.

Results: The files of 979 eligible terminal cancer patients were analyzed: the number of patients in the OME cohorts between none opioids and >900mg/d were respectively: 156, 533, 156, 52, en 82 patients. Analysis shows that stable doses of opioids with small standard deviations up to 4 months before death could control pain in these large number of patients. There was a slight but statistically non significant increase of opioid consumption in the last few days.

Conclusion: Tolerance to strong opioids is not a real clinical issue in the last months before death. The myth of tolerance to strong opioids can no longer justify postponement or withdrawal opioids in terminal cancer patients. These data enforce us to prescribe strong opioids in time and in proportion to pain intensity as soon as moderate or severe pain is present.

Health care services I

Abstract number: OA19
Abstract type: Oral

Effectiveness and Cost-effectiveness of Home Palliative Care Services: A Meta-analysis

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Aims: To quantify the effect of home palliative care for patients with advanced illness and their caregivers on the odds of dying at home, examine effects on other outcomes and determine cost-effectiveness.

Methods: We searched 12 biomedical databases (May 2010); checked references from included studies, 49 systematic reviews, 4 textbooks, conference abstracts; contacted 17 researchers for data. Inclusion criteria: RCTs, CCTs, controlled before and after studies (CBAs) and interrupted time series evaluating the impact of home palliative care on outcomes for adults with advanced illness and/or family caregivers. One reviewer assessed titles/abstracts; two independently assessed relevant studies, extracted data and assessed methodological quality. We carried out meta-analysis and calculated numbers needed to benefit (NNTB) for death at home.

Results: There were 23 studies including 37,561 patients (4042 family caregivers) largely with advanced cancer but also CHF, COPD, HIV/AIDS and MS among other conditions. Meta-analysis showed increased odds of dying at home (OR 2.21, 95% CI 1.31 to 3.71; NNTB=5 (seven trials; 1222 patients)) and moderate evidence of small but statistically significant effects of home palliative care services on reducing symptom burden for patients (three trials and one CBA; 2157 patients) compared to usual care. Evidence on cost-effectiveness was inconclusive.

Conclusion: We found clear and reliable evidence that home palliative care increases the chance of dying at home and reduces symptom burden, in particular for cancer patients. This justifies provision for those who wish to die at home. Research needs to study cost-effectiveness especially for non-cancer patients, assess place of death and appropriate outcomes which are sensitive to change and valid in these populations, and compare different models of home palliative care in appropriately powered trials.

Funding: Cicely Saunders International and Calouste Gulbenkian Foundation.

Abstract number: OA20
Abstract type: Oral

Hospital Nurses: What Do they Know and what Do they Think of Palliative Care?

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In the Netherlands 30,000 people die each year in the hospital and many more patients admitted to hospitals are in need of palliative care (PC). Providing PC requires special knowledge and attitudes of nurses.

The aim of this study was to get insight in opinions and knowledge on PC of general hospital nurses.

We took a random sample of 477 nurses, all working on one of 17 general wards in a Dutch university hospital. They were asked to fill in the electronic MOVE2PC questionnaire containing topics on characteristics, opinions and subjective norms, potential dilemmas in PC and knowledge statements. We analyzed data on knowledge and opinions.

25% (n=120) completed the questionnaire; 88% female, 56% < 30 years. Respondents were students (13%), staff nurses (49%), senior staff nurses (4%) or other nurses (36%), 54% had > 5 years experience as a nurse. 82% spent < 25% of their time on providing PC.

Nurses answered 10.2 (SD 3.0) out of 20 knowledge statements correctly: 1.2/5 (SD 1.2) statements on disease specific symptoms, e.g. the prevalence of pain in chronic heart failure and 9.0/15 (SD 2.4) statements on general symptoms and care, e.g. constipation. Most nurses (64%) had had < 1 day PC education after their initial professional education. This was the only nurse characteristic related to knowledge: nurses who had had PC education gave significantly more correct answers than nurses who had not had this education (11.3 versus 9.6).

A large majority of the nurses thought PC should include spiritual care (84%) and care for the relatives (98%). 43% of the nurses agreed with the statement that PC can be combined with intensive life prolonging treatment. Nevertheless 52% thought that life prolonging treatment is often continued too long in the hospital.

We conclude that hospital nurses have limited knowledge on PC but education seems to be beneficial. They share some opinions and subjective norms on palliative care, but vary in opinions on providing PC in the hospital.

Abstract number: OA21
Abstract type: Oral

Strategy to Improve Palliative Care Delivery at Regional Level: Madrid Primary and Secondary Care Single Referral Document. Design, Adoption and Implementation

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Introduction: Madrid Strategic Plan outlines palliative care organization underpinned by the development of new technologies for its 6.5 million population of which some 20000 need specialist Palliative Care (PC) each year.

Objective: To design and develop a single referral protocol for all patients needing PC regardless of age or health care level helping referee decide on the appropriate referral time, diagnosis and disease trajectory point by trigger points for each.

Methods: A task group was set up to work for three months: specialist professionals reviewed 7 different documents in use from which a consensus protocol was drafted and piloted for 3 months by all 43 regional PC teams.

Results: Madrid has a single Referral Document for all adult and pediatric patients whether their disease is oncological or non-oncological. It reflects demographic data, referral reason, primary diagnosis, clinical information and medical history summary. It incorporates a integrated and multidisciplinary assessment physical, psycho-emotional, spiritual and socio-familiar needs. A year later its electronic format is standard for all professionals in all settings.

Conclusions: A single point of entry by the same referral document offers discernible benefit for patient access to timely PC. Unifying patient information has been essential for a comprehensive and multidisciplinary approach and to raise professional awareness of PC resources. Continuity of care is now a reality in Madrid as seen by improvement in Quality Indicators referring to referral numbers and early identification.

Our experience demonstrates it can be done for a whole region. We are currently collecting improvement proposals from all professionals.

With our most sincere thanks to all Community of Madrid PC Professionals.

Abstract number: OA22
Abstract type: Oral

How Can We Optimise Palliative Care Management in Acute Hospitals? Lessons from New Zealand

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Aims: To explore the current management of patients with palliative care needs experiencing a hospitalisation in one acute hospital setting in New Zealand.

Methods: The study was conducted in 4 phases:
1) qualitative interviews and focus groups involving 39 clinicians;
2) a census of palliative care needs amongst 500 inpatients;
3) an economic analysis; and
4) a survey of 599 clinicians.
Results: Qualitative interview and focus group data results identified problems with communication regarding goals of care and prognosis between clinicians and patients. Particular challenges in providing culturally appropriate end of life care to the diverse ethnic mix of patients in New Zealand were reported. Census results included the following: 19.6% of inpatients were identified as having palliative care needs; 19.2% of these admissions were considered to have been potentially avoidable. Almost 50% of admissions had resulted from a presentation to the Emergency Department. The education needs survey identified that 18.8% of participating clinical staff had undertaken a formal training course in palliative care. An association between received formal education in palliative care and perceived comfort in palliative care management was identified.

Conclusion: This study identified areas where palliative care management could be optimised, notably in relation to patient communication regarding goals of care and improving clinician confidence to discuss end of life issues with patients from diverse cultural backgrounds. A need for further palliative care education for medical and nursing staff working within acute hospital settings is therefore evident. Findings from this research will inform intervention studies that aim to optimise palliative care management in the acute hospital setting.

Abstract number: OA23
Abstract type: Oral

Multidisciplinary Palliative Care Provision and Palliative Care by General Practitioners: A Comparative Study via GP Networks in Belgium, Italy, the Netherlands and Spain

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Background: Population-based studies comparing palliative care service use across countries, diseases and care settings are scarce. This study compares the use of multidisciplinary palliative care initiatives (MPCI) and palliative care provided by general practitioners (GPs) in four European countries and analyses determinants of receiving these types of care across countries.

Methods: As part of the Euro SENTI-MELC study, GPs from Belgium (BE), the Netherlands (NL), Italy (IT) and Spain (ES) completed registration forms about their patients who died. Care in the last three months of life, pathology and patient characteristics were registered. Sudden deaths were excluded. Analysis was performed using X2-tests and logistic regression.

Results: We studied N=4,518 patients dying non-suddenly (aged ≥18y). MPCI were most frequently received in ES (48%) and BE (44%) and less often in NL (31%) and IT (38%) (p< 0.05). GPs were most likely to deliver palliative care in ES (61%) and less likely in BE (50%), NL (55%) and IT (55%) (p< 0.05). These differences remained significant after adjustment for place and cause of death, age and sex. Across countries, cancer patients received more MPCI and palliative care by a GP. Older patients and patients dying in hospital (excluding palliative care unit [PCU]) as compared to those dying at home received MPCI less often, whereas patients dying in a care home or PCU/hospice received it more often. Fewer of those dying in a hospital, PCU/hospice or care home received GP palliative care compared to those dying at home.

Conclusion: GP palliative care was most often delivered in ES, MPCI most often in ES and BE. Reasons for these differences should be explored. An important role of the GP in palliative care for the elderly is suggested as older patients received less MPCI but not less GP palliative care. Previous reports showing that non-cancer patients and those dying in hospital are less likely to receive palliative care are supported.

Abstract number: OA24
Abstract type: Oral

Do Interventions Designed for ‘Home Alone’ People Dying from Cancer Improve their End of Life Experience?

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Aims: This project implemented and evaluated two models of palliative care service delivery for terminally ill people with cancer and living alone at home, in collaboration with Silver Chain Hospice Care Service. The aim was to assess the impact of the models of care on the participants’ quality of life, symptom distress, anxiety and depression, satisfaction with care and perceived benefits and barriers to using them, from patients’ and service providers’ perspectives.

Methods: Two models of care were piloted and evaluated: Installing CareLink Alarm systems and providing extra care
Junior Forum

Abstract number: INV5
Abstract type: Invited Speaker

Don’t Miss Out: Managing Missing Data

Fayers P.

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Missing data is a particular problem in palliative care clinical trials, especially when asking patients to complete questionnaires health-related quality of life or other patient-reported outcomes such as pain, cachexia and fatigue. The problems are twofold. Firstly, in this setting there is frequently a considerable amount of missing data, because patients are too ill or too frail to complete questionnaires. Secondly, this missingness tends to be associated with the most ill patients, and so simply ignoring those patients who have data missing may result in misleading bias in the analysis of clinical trial results.

In recent years there have been considerable advances in the statistical approaches to try to alleviate the problems of analyzing trials where there is missing data, and we review the range of methods.

The aim of statistical methods is to minimize bias. Ultimately, however, there is no ideal way to compensate for the real data. Every effort should be made to maximize compliance and to collect patients’ data wherever possible.

Abstract number: INV6
Abstract type: Invited Speaker

Different Approaches to Care at the End of Life: A Transcontinental Study Utilizing Key Informant Interviews

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Background: Despite national strategies or frameworks for care at the end of life, many terminally ill patients still do not die at their preferred location or under the form of care desired. The study identified barriers and facilitators to hospice palliative care service provision in four target countries (Canada, England, Germany and United States of America) from a health services research perspective.

Methods: Document analyses, literature reviews and key informant interviews were employed to identify system-level characteristics - including legislation, regulation and financing - influencing service delivery, care outcomes and costs. Challenges to data gathering, warehousing and analyses are highlighted and solutions discussed.

Results: Although core elements of disease management and bereavement care were addressed in the various models of care employed, their extent, level of interdisciplinarity and integration into the health care system varied between countries and by disease classification (cancer/non-cancer). The availability of financial and of health human resources (HHR) were identified as critical barriers to service provision, as were regulatory issues and education and training for service providers (including volunteers). Key informants suggested that a formal end-of-life care strategy (potentially following a national cancer strategy and including advance directive provisions) might assist with addressing those barriers and increase effective and efficient service delivery across the continuum and across settings.

Conclusion: Country specific service approaches provide a scope for mutual learning/best practice adaptation. National strategies need to be: specifically tailored to the health care environment, inclusive, culturally sensitive and aimed toward the integration of hospice palliative care into the health care system. A detailed research plan - and patience - are needed to successfully accomplish projects across continents.

Abstract number: INV7
Abstract type: Invited Speaker

All Mixed Up? Using Mixed Methods Methodology to Evaluate Complex Interventions

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Background: There is increasing interest in ‘mixing’ or combining qualitative and quantitative research methods to provide a deeper and paradoxically more comprehensive insight into palliative care-related issues.

Aims: The purposes of this presentation is to position mixed methods research as the natural complement to...
traditional qualitative and quantitative research, to present pragmatism as offering an attractive philosophical partner for mixed methods research, and to provide a framework for designing and conducting mixed methods research with specific reference to evaluating complex interventions.

Content: Useful texts are highlighted and illustrative examples provided of mixed method studies in palliative care, including detailed worked examples in the development and evaluation of complex interventions in palliative care for breathlessness and the delivery of end of life care in critical care settings. Key challenges to conducting mixed methods in palliative care research will be identified in relation to data collection, data integration in analysis, costs and dissemination and how these might be addressed.

EAPC Research Network

Abstract number: INV8
Abstract type: Invited Speaker

Status Today of Public Health and Health-Services Studies

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More than 50 million people worldwide die each year and it is estimated that between 40% and 60% of them could benefit from some form of palliative care. Ensuring that these people have access to adequate palliative care presents an important challenge to the public health. Irrespective of the variation in the factors impeding a ‘good enough death’ between different parts of the word and between different health care settings, safeguarding good quality of life at the end of life for eligible patient populations essentially requires a public health approach.

Next to the rapid grow in clinical studies in palliative care, in the last decades, there is also a rapid development of public health and health services research. While clinical studies are focused on generating evidence for clinical interventions in palliative care, health services research generate complementary knowledge on the organisation aspects of palliative care and the patients’ and professionals’ experiences with these palliative or end of life services. While health services evaluation will be focused on the evaluation of the care giving processes of one or more particular services, public health studies will be more focused on patient populations or global populations. In order to stimulate growth and quality in palliative care (research), next to clinical research, also good quality studies in public health and health services research are needed.

In this presentation Luc Deliens will review the strengths and weaknesses of public health and health services research in palliative care in Europe, and will present some of the ongoing projects of EAPC RN in these domains.

Abstract number: INV9
Abstract type: Invited Speaker

Status Today of Clinical Studies

Kaasa S.1,2
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EAPC RN are inviting all health care professionals who see potential in conducting multicentre research. Very few large scale clinical trials (CT) that may guide clinical practice have been conducted in palliative care. EAPC RN have recently conducted and published results from observational/cross-sectional design large scale CT’s in the area of pain (EPOS) (1), symptom assessment and classification (CSA) (2) and limitations and barriers to conducting multicentre research have been identified (3). By conducting 22 systematic literature reviews and development of the latest version of the EAPC guidelines for treatment of cancer pain with opioids (4), one striking finding was the low level of evidence recommendations were based upon (5). In order to conduct interventional CT’s in the future, the PRC was established in 2009 with the support from EAPC. The PRC will plan and conduct intervention CT’s across Europe and worldwide. Studies are running, such as the MENAC study, the TvT study, the Nasal Fentanyl study and the EPCCS study (6, 7).

References:
Abstract number: INV10
Abstract type: Invited Speaker

Basic Science Research: How to Plan and Collaborate
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Any functional and therefore productive collaboration must draw together a group of people with a common interest and desired endpoint. Our traditional thought of palliative care research has not involved basic scientists and realization that this might be not only useful but critical in expediting symptom control research has been relatively recent. Like all good collaborations the common interest is established through effective communication. The best collaborations have both good clinical communicators but also excellent basic science communicators and the process is not unidirectional but rather is iterative.

Collaborations which are somewhat forced because translational research seems fashionable and may attract grants, will usually be short-lived. To find an effective collaboration it therefore follows that geographical proximity is not the key factor and indeed it is much better to be working with the right group of people than have a forced local collaboration. Like all effective communication, sufficient time and thought have to be invested and collaborations between basic scientists and clinicians will not grow up over night, but have to be carefully nurtured. I am going to describe and iterative programme of translational research involving our animal model of cancer-induced bone pain (CIBP), along with the clinical paradigm of patients with metastatic bone pain receiving palliative radiotherapy.

The aim of this basic science collaboration in Edinburgh, with support from Prof Dickenson’s laboratory at UCL, was to 1) develop an animal model of CIBP 2) characterize the animal model 30 characterize in the clinic CIBP including clinical biomarkers 4) examine in both the animal model and in the clinic changes in both characteristics and biomarkers after receiving standard palliative radiotherapy for CIBP 5) establish congruence between the animal model and the clinical situation 6) examine treatment in animal model and translate appropriately.

Abstract number: INV11
Abstract type: Invited Speaker

How to Set the Future Research Agenda of Clinical Research
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Two major reasons establish the need for research in palliative care. First, a new field of medicine such as palliative care has to stand up to the standards of medical care and provide the evidence base for palliative care interventions to proof that it is doing what it says it does. Secondly and more important, palliative care patients have a right to receive the best treatment available, and this means that treatment options have to be compared to identify the optimal intervention.

However, up to now there is a dearth of research in most areas of palliative care. This is partly due to lack of funding or of research capacities in palliative care centres, but also to methodological problems, such as low recruitment rates and high attrition rates in clinical studies.

In some areas of palliative care patients and care givers preferences have to be assessed in order to formulate hypotheses and epidemiologic background data are needed in order to obtain baseline values for subsequent clinical intervention studies. New research methodologies have been suggested to overcome methodological problems, for example n-of-1 trials where every patient is his own control. Examples from other fields of medicine such as intensive care or geriatrics can be helpful as well to overcome methodological problems, such as obtaining informed consent from cognitively impaired patients.

Considering the scope of clinical research in palliative care, from needs assessment to controlled clinical trials, and including research on methodology and on ethical issues, a research agenda is needed to describe the field of research and to set priorities in clinical research. Such an agenda could be used to inform funders, allowing a structured and rapid development of palliative care research in the next years. The German Academy of Science has just initiated a working group to set up such an agenda for Germany, and this may be used as a model on a European level subsequently.

Abstract number: INV12
Abstract type: Invited Speaker

How to Set the Future Research Agenda of Health-Services Research
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Aims: Patients, families, practitioners, managers and other stakeholders are well positioned to comment on the future research agenda in palliative and end-of-life care. This paper explores how different perspectives can be elicited to influence future research.

Methods: Drawing upon contemporary public and patient involvement initiatives in the United Kingdom, and a five year programme of work involving service users (called Research Partners) from the Cancer Experiences (CECo),
this paper offers a synthesis of approaches and evaluates their strengths and limitations.

**Results:** Evidence from the literature on public and patient involvement in setting research priorities indicates that service users are able to identify research objectives that take account of more than their own needs or perspectives. For example, in cancer they have been shown to highlight that communication and information provision are rated more highly than treatment related research, and many wish for more research to address the experiences of living with the disease and its treatment. The CECo Research Partners (a group of patients and families who guide and advise on health services research) provide an important balance to clinical or organisational research agendas by contributing their ‘real world’ experiences of living with, or caring for a person with, advanced disease.

**Conclusions:** Practitioners and researchers are encouraged to reflect on how behaviours and communications may be interpreted to identify and prioritise research topics so that language and formats offer opportunities for inclusiveness to all groups in society who may benefit from improvements in palliative and end-of-life care services. Attention also needs to be given to the changes in practice and organisation of research agenda setting to facilitate more positive experiences for patients and families to contribute.

### Plenary session II

**Abstract number:** INV13

**Abstract type:** Invited Speaker

**The Scientific Contribution of Psychosocial Research in Palliative Care**

*Rodin G.*

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Attention in palliative care to the psychosocial and spiritual dimensions of illness has revolutionized not only end-of-care but also the entire field of Medicine. Research in the field has emerged to clarify constructs, such as spiritual well-being, existential distress, demoralization, dignity, posttraumatic growth and the desire for hastened death, that are not well captured by traditional measures of psychopathology. Evidence has also been generated about the clinical relevance of subsyndromal symptoms of depression, anxiety and posttraumatic stress, which are the most common presentation of these disturbances in palliative populations. The development and evaluation in randomized controlled trials of semi-structured interventions to relieve distress and to promote psychological growth has also significantly advanced research and clinical care. International collaborations are beginning to elucidate the acceptability and success of these interventions in settings that differ in terms of religion, culture, attitudes about death and dying and access to clinical resources. Challenges remain about how to apply these approaches in busy clinical settings and how to integrate disease-based, symptom-based and psychosocial care in patients with advanced and terminal disease. However, what is incontrovertible is that the culture of good intentions in palliative care has been augmented by a new science of psychosocial care.

**Abstract number:** INV14

**Abstract type:** Invited Speaker

**How Do We Measure Spiritual Outcomes? Lessons from Exploring the Construct of Peace in an African Setting**

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**Background:** Culturally sensitive measurement of spiritual well-being (SWB) is essential to screen for spiritual distress, evaluate spiritual care (SC) interventions and assess the quality of SC, but there is little evidence in this area to inform service provision and research in sub-Saharan Africa.

**Aim:** To explore the utility of the APCA African Palliative Outcome Scale (POS) peace item - “Over the past three days, have you felt at peace?” 0 (No, not at all) - 5 (Yes, all the time) - as a measure of SWB in palliative care patients in South Africa and Uganda.

**Methods:** Secondary analysis of data from a cross-sectional survey of 285 patients using the POS and Spirit 8, and from qualitative interviews with 72 patients. Findings were integrated with fieldwork data from SC providers, researchers who collected the patient data and local experts. Statistical analysis determined levels of peace, correlations of peace with POS and Spirit 8 items, and associations between peace and other variables. Content analysis of qualitative data identified interpretations of peace and facilitators/barriers to feeling at peace.

**Results:** 27% of patients scored poorly on levels of peace. Peace correlated moderately with POS life worthwhile (rho = 0.35, p< 0.001), Spirit 8 SWB (0.46, p< 0.01) and Spirit 8 affairs in order and comfort with the thought of death (both 0.34, p< 0.001). Peace was positively associated with POS ability to share and help and advice to plan for the future, and time receiving palliative care. Peace was interpreted in relation to perception of self/world, relationships, spiritual beliefs, and health/healthcare. Facilitators/barriers were multidimensional and often related to everyday (e.g. socioeconomic) concerns.

**Conclusions:** This study highlights the utility and limitations of the POS peace item as a measure of SWB in African populations. Findings were used to develop SC recommendations. Implications for European clinicians and researchers will be discussed.
Clinic, Trondheim, Norway, 3Fondazione IRCCS Istituto Olavs Hospital, University Hospital of Trondheim, Cancer Palliative Care, Department of Oncology, Oslo, Norway, 4Oslo University Hospital, Ullevål, Regional Centre for Excellence in and Rehabilitation Unit, Milano, Italy, 4Oslo University Nazionale dei Tumori, Palliative Care, Pain Therapy

Conclusion: all three domains did when completed by the patients. none of the HCP-rated KDs contributed significantly, while model. When combining all predictors in a single model, HCP model was 5% compared with 19% in the self-report model. When assessing pain, the ECS-CP is rated by a health care provider (HCP), while it has been repetitively recommended that subjective symptoms should be assessed by the patients. We hypothesize that self-report of the KDs of the ECS-CP using standardized instruments provides a better explanation of the variance of pain as an outcome than when using HCP assessments in the ECS-CP.

Aims: An appropriate diagnostic workup is crucial for adequate treatment of cancer pain. Breakthrough pain (BTP), neuropathic pain (NP), and psychological distress (PD) have been reported as the key domains (KD) of the ECS-CP. The ECS-CP is rated by a health care provider (HCP), while it has been historically recommended that subjective symptoms should be assessed by the patients. We hypothesize that self-report of the KDs of the ECS-CP using standardized instruments provides a better explanation of variance of pain as an outcome than when using HCP assessments in the ECS-CP.

Methods: Patients with advanced cancer were recruited in eight countries (17 centres). The ECS-CP was completed by a HCP. Patients rated pain intensity on a 0-10 numerical rating scale (NRS-11), BTP on the Alberta Breakthrough Pain Questionnaire, NP on the Pain Detect, and PD was assessed by the depression item of the Edmonton Symptom Assessment System (ESAS, NRS-11). Adjusted R² from linear multivariate regression models with pain intensity as dependent variable was used to compare the explicative power of the three KDs respectively rated by the HCPs or by the patients.

Results: The analysis included 617 advanced cancer patients with pain (mean 0-10 NRS score 3.7) and 48% reported pain >3. The amount of variance explained by the HCP model was 5% compared with 19% in the self-report model. When combining all predictors in a single model, none of the HCP-rated KDs contributed significantly, while all three domains did when completed by the patients.

Conclusion: In this large international multicentre study, patients’ self-report of breakthrough pain, neuropathic pain, and psychological distress were significantly better in explaining pain than health care providers’ rating of the same three KDs. These findings indicate that standardized patients’ rating may improve cancer pain classification.

This study was supported by the EU’s 6th framework, contract no. 037777 (EPCRC).

Symptoms other than pain I

Abstract number: OA25
Abstract type: Oral

A Randomised Double Blind Placebo Controlled Trial of Infusional Subcutaneous Octreotide in the Management of Malignant Bowel Obstruction in People with Advanced Cancer

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Bowel obstruction due to advanced cancer that is surgically inoperable is a major management problem. Studies to date have either been underpowered or have used comparators that may not draw on the best available evidence.

Methods: This double-blind, block randomised, placebo controlled, set dose, parallel arm study was conducted across 12 sites in Australia. Eligibility included inoperable bowel obstruction secondary to cancer or its treatments. The intervention was the addition of infusional octreotide or placebo in addition to 200mg ranitidine per 24 hours parenterally and 4mg per 24 hours parenterally of dexamethasone. The primary outcome measure was the numbers of days free of vomiting up to 72 hours after all medications were administered the first time. Participants were also administered between 10-20mls per hour of subcutaneous isotonic fluid over the 72 hour period.

Results: This study will close to recruitment in November 2011. To date 91 of 92 required participants have been randomised.

Discussion: This adequately powered study will define the additional net clinical benefit derived from octreotide over placebo in people who have an anti-secretory agent (ranitidine) and glucocorticoids (dexamethasone).

Abstract number: OA26
Abstract type: Oral

Cancer Patients Treated with Opioids Have Poor Sleep Quality
Aim: The aim is to evaluate the sleep quality in cancer patients treated with opioids.

Methods: The study is a cross sectional study with cancer patients using opioids (Step III at the WHO treatment ladder for cancer pain). Sleep was assessed by the Pittsburgh Sleep Quality Index (PSQI). The PSQI have 19 items grouped into 7 component scores, each weighted equally on a 0-3 scale to provide a global sleep quality score ranging from 0 (high quality of sleep) to 21 (low quality of sleep). A score above 5 indicate poor sleep quality. Pain was assessed by the Brief Pain Inventory and quality of life (e.g. sleep latency).

Results: 604 of 931 patients answered the PSQI. Mean Karnofsky score was 62.5 (SD 14.2), median age was 62 years and 58% were men. The most frequent cancer diagnoses were gastrointestinal cancer (23%), lung cancer (19%) and prostate cancer (15%). The mean opioid equivalent morphine dose was 330 mg. Forty percent used steroids, 22% used antidepressants, 18% used benzodiazepines and 12% used hypnotic drugs. The mean global sleep quality score was 9.08 and 73% of the patients had a score of > 5 indicating poor sleep quality. Patients with poor sleep quality had significantly lower Karnofsky Performance score (62 vs. 67) and reported more average pain (3.7 vs. 3.1). Nausea and vomiting, fatigue, emotional function, dyspnoea and constipation were worse in patients with poor sleep. Disturbance of sleep quality was observed across all component scores of the PSQI. The most affected subscales were sleep disturbance, daytime dysfunction and sleep latency.

Conclusion: The majority, 73%, of cancer patients using opioids were identified as having poor sleep quality and all components of sleep quality were affected. Patients with poor sleep quality had lower physical performance and reported more pain, nausea, vomiting, fatigue, dyspnoea and constipation.

Source of funding: Norwegian Research Council, The Norwegian Cancer Society and The Norwegian Nurses Organisation
well-being depends on life circumstances and concerns which are not necessarily related to illness or to spiritual questions per se (e.g. socioeconomic problems). Services can support patients' spiritual well-being by considering the identified facilitators and barriers and by providing excellent holistic care and targeted, individualised interventions.

**Funders:** Halley Stewart Trust

**Abstract number:** OA28

**Abstract type:** Oral

**The Effectiveness of Protocolized Treatment of Physical Symptoms in Improving Cancer-related Fatigue: A Randomized Controlled Trial**

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**Aim:** As part of the treatment of cancer-related fatigue, several guidelines advise to optimize treatment of accompanying symptoms. However, this recommendation is only based on the correlations between symptoms and fatigue. Therefore, we investigated if monitoring and protocolized treatment of physical symptoms decreases fatigue severity.

**Methods:** Advanced cancer patients with a fatigue score ≥4 on a 0-10 NRS were randomized to monitoring and protocolized treatment of symptoms (PT) or standard care (SC), stratified for tumor treatment. In 2 months, patients in the PT-arm had 4 appointments with a nurse who assessed pain, nausea, vomiting, diarrhea, constipation, anorexia, breathlessness, cough and dry mouth on a NRS. Patients received a non-pharmacological intervention for symptoms with a score ≥1 and a causal or symptomatic medical intervention for symptoms with a score ≥4. Fatigue (Multidimensional Fatigue Inventory and NRS), daily interference (Brief Fatigue Inventory), symptom severity (total score of the nine physical symptoms (EORTC-format)), quality of life (7-point EORTC-scale), anxiety and depression (Hospital Anxiety and Depression Scale) were measured at baseline, and after 1, 2 and 3 months. Group*time differences in the outcome variables were assessed using mixed modeling. 152 patients were planned to be randomized: PT Group 76, SC group 76. We found a greater decrease over time in fatigue (MFI-GF, p=0.045; and NRS, p< 0.001), interference of fatigue with daily life (p=0.001) and symptom burden (p=0.002) in the PT-group than in the SC-group. There were no significant differences in the other MFI-subscals and in anxiety and depression.

**Conclusions:** Monitoring and protocolized treatment of physical symptoms improves fatigue, interference of fatigue with daily life and symptom burden in fatigued advanced cancer patients.

**Abstract number:** OA29

**Abstract type:** Oral

**Cognitive Behavioural Therapy (CBT) for Panic and Anxiety in Chronic Obstructive Pulmonary Disease - A Systematic Review**

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**Background:** Anxiety and panic are common symptoms in chronic obstructive pulmonary disease (COPD). Models for the development of panic symptoms suggest that cognitive-behavioural therapy (CBT) may be effective for treating the negative thoughts leading to symptoms of panic and anxiety.

**Aim:** To evaluate the effectiveness of CBT for the treatment of mild - severe anxiety and panic in adult patients with mild-severe COPD.

**Methods:** Systematic review of (randomised) controlled trials. In addition to hand and reference searches the databases Medline, Embase, PsycInfo, British Nursing Index and Archives, ASSIA, CINAHL, and the Cochrane Library (from 1950 until August 2011) were searched with a combination of keywords and subject headings for COPD, anxiety/panic and CBT. Studies were included which used specific cognitive as well as behavioural techniques for COPD patients of all stages with mild-severe panic or anxiety symptoms in any care setting. Meta-analysis for different outcome measures was calculated.

**Results:** Of 7,138 retrieved references, 13 studies were included. Seven of 13 studies reported a significant impact of CBT on anxiety. Only one study investigated the preventive effect of CBT on panic and demonstrated a risk reduction for the development of panic attacks and a reduction in anxiety. In contrast, six other studies, one of which was an adequately powered RCT, failed to show an improvement in anxiety symptoms. There was large heterogeneity in the CBT intervention delivered and in the methodological quality of clinical studies. The meta-analyses showed a small effect of CBT on anxiety.
Conclusions: There is only weak and conflicting evidence for the effectiveness of CBT in COPD patients due to under-powered and small-scale studies. An adequately powered RCT disentangling the contributions of exercise training, education, and CBT in a COPD population with clear in-and exclusion criteria for anxiety and panic severity is needed.

Source of funding: None.

Poster discussion session 1

Abstract number: P80
Abstract type: Poster Discussion

Preparing Patients for Death: Nursing Students’ Concerns in Three Countries

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Introduction: Caring for patients who are dying is integral to the art and science of nursing.

Understanding the similarities and differences between nursing students regarding their concerns about their own death and caring for patients who are dying will assist academic and clinical educators address their needs more effectively.

Purpose: To describe and compare concerns about dying for nursing students from California, Norway and Sweden.

Design: Longitudinal cohort study. The first results of three years is presented here.

Sample First year nursing students (n=514) were invited to participate. 389 (76%) responded California students n=142 (71%) Norwegian students n=106 (68%) Swedish students n=141 (89%) 

Methods: Data collection: Four background questions (age, experience in health care, previously attended a dying patient and age in encountered death of a loved one) and two instruments were used. The Concerns about Dying (CAD), sub dimensions; general (4 items), spirituality (3 items) and patient-related (3 items) (Mazor, et al 2004) Sense of Coherence (SOC) (13 items) (Antonovsky 1993).

Findings:
- Norwegian and Swedish students had attended significantly more dying patients (p = 0.000) than students from California and they were younger when they first encountered death of a loved one (p = 0.005).
- Concerns about dying
- Statistical significances were found between the students regarding the three subscales of CAD.
- The students in Sweden had least concerns about there own death (p = 0.000)
- The students from California were most likely to endorse spiritual use (p = 0.000)
- Swedish students were more comfortable working with dying patients (p = 0.000)

Sense of coherence:
- No significant differences were found between the students

Conclusions: Prior to requiring participation in end of life learning experiences in the classroom and during clinical educators may want to consider assessing student concerns about death in order to facilitate achieving expected learning outcomes.

Abstract number: P214
Abstract type: Poster Discussion

Exploring how the MRC Complex Intervention Framework Explained the Sequential Practice-based Research Steps Undertaken to Develop End of Life Care in Nursing Homes

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Background: In 2000, little was known about the quality of care for frail older people dying in nursing homes (NHs). The increasing pressure on NHs to develop end of life care made it an ideal setting for practice-based research; but with less than 10% NH residents having a cancer diagnosis, it was important not just to impose a specialist palliative care model. The sequential steps of the MRC complex intervention provides a framework by which to explore different practice-based research undertaken.

Methods: Pre-clinical & Phase I: an ethnographic study of death/dying in 2 NHs followed by an action research intervention to understand: What problems do staff experience in their care of dying residents? What interventions do staff feel appropriate in order to create a palliative care approach? Phase II: two feasibility studies to see whether the implementation of end of life care tools improved care and avoided inappropriate hospital deaths. Phase III: a cluster randomised control trial across 24 NHs to investigate ‘facilitation’ when implementing end of life care tools, to answer: What type of facilitation reduces the proportion of hospital deaths and improves staff’s ability to provide good end of life care? What are the cost-benefits between different models of ‘facilitation’?

Results: Phase I revealed that dying was peripheral to the NH culture. It highlighted the importance of the lifeworld (valuing staff) and system (structures such as end of life care tools) when bringing about change in NHs. Phase II identified that high facilitation was important when implementing end of life care tools as NHs have a weak context (high staff turnover; majority of staff are untrained; limited
medical input). Phase III’s data collection is complete and analysis is on-going.

**Conclusion:** It is proposed that the above sequential research studies albeit intuitively undertaken could be seen to incorporate the iterative development of a MRC complex intervention to inform the final phase.

**Abstract number:** P27
**Abstract type:** Poster Discussion

**Symptom Prevalence in Advanced Cancer: Age, Gender, and Performance Status Interactions**

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**Objectives:** Multiple factors likely influence symptom prevalence in cancer. We report 8 symptoms whose prevalence were associated with more than one of the 3 demographic characteristics of age, gender, and performance status (PS).

**Methods:** 38 symptoms were assessed in 1000 consecutive advanced cancer patients. The association of 3 demographic factors with each symptom was examined using logistic regression analysis. The prevalence of 8 symptoms were associated with more than one of the three. Model-based prevalence estimates were calculated for 30 groups based on combinations of age (45, 65, 85 years), gender (female, male), and ECOG PS (0-4). Prevalence differences between various groups were calculated; values >10% were empirically classified as clinically relevant.

**Results:** All 3 demographic factors were significantly associated with the prevalence of only one symptom, anxiety. The frequency of all 8 decreased with older age. Females had a higher prevalence of nausea, anxiety, and vomiting than males; males had more sleep problems. Prevalence of constipation, sedation, and blackouts was higher with worse PS, whereas both pain and anxiety became less common with worse PS. We observed 2 major patterns: PS had the largest influence on prevalence, followed by age and then gender. This included pain, constipation, anxiety, sedation, and blackouts. In the second pattern age had the largest influence on prevalence, followed by gender and then PS; this affected sleep problems, nausea, and vomiting.

**Conclusions:** Age, gender, and PS appear to interact with each other and be associated with variations in the prevalence of 8 symptoms in advanced cancer. 2 major interaction patterns were noted; PS was dominant in one, age in the other. These 3 demographic characteristics should be included as important variables for consideration of symptom burden in clinical practice, in the design of symptom research studies, and analysis of data.
Supporting Family Carers: The Relative Importance of Different Support Domains in Explaining Negative and Positive Impacts from Caregiving

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Aims: The study aim is to investigate the relative importance of different support domains in explaining negative and positive impacts from care giving. End of life care at home is highly dependent on the efforts of family carers. They often suffer negative effects from care giving, but can also experience positive effects. To improve outcomes for carers we need to understand what domains of support are most important in explaining adverse impacts and positive experiences from care giving so that support can be targeted appropriately.

Sample: Six UK hospice home care services identified the main carer of all patients active on their caseload. N=225 carers participated (25% response rate).

Methods: Postal survey. Need for support was measured through 14 core support domains of the Carer Support Needs Assessment Tool (CSNAT). Carer Strain, Distress, Positive Appraisals, Global Health and Preparedness were measured through standard measures.

Analysis: Linear regression analysis was conducted to examine the associations between the support domains and carers’ perceived Preparedness, Global Health, Strain, Distress and Positive Appraisals. The Pratt Index was used to evaluate relative importance.

Results: Lack of daytime and night-time respite and not knowing what to expect in the future, were the most important CSNAT domains in explaining negative effects from care giving. Overall lack of support explained the greatest variance in global health (35%), Distress (33%) and Preparedness (27%), but showed little relation to Positive appraisals (8%). Details of the relative importance of each support domain on each type of adverse effect will be presented, as well as intergenerational differences in patterns.

Conclusion: Adverse effects from care giving may be ameliorated by targeting particular support domains, specifically respite and future expectations. Conversely, positive experiences may mainly be determined by other factors than support.
Abstract number: P43
Abstract type: Poster Discussion

Translation and Cross-cultural Adaptation of the Palliative Performance Scale Version 2 (PPSv2) into Spanish

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Introduction: The PPSv2 measures the functional status of patients receiving palliative care. Outcome measurement has a major role to play in improving quality, efficiency and availability of palliative care.

Aims: To translate the PPSv2 into Spanish and to assess its cross-cultural validation.

Methods: The process was designed in 2 phases.
Phase 1: Translation process was obtained using a reverse translation method by 4 competent health bilingual professionals. Grammar, linguistics and semantics were corrected to detect comprehension problems by 2 experts in Spanish grammar, and reviewed by the researchers to ensure its equivalence with the original text. The reverse translation into British and American English was back translated by 2 bilingual English native speakers.
Phase 2: The assessment was carried out on 30 consecutive patients admitted in the oncology ward in two different moments (day 0 and day 2) by 4 different health professionals (2 nurses and 2 doctors). Inter-observer reliability and intra-observer reliability were calculated with test-retest method. To assess the inter-observer and the test-retest reproducibility, we calculated the intra-class correlation coefficient (ICC). The professionals were trained before the administration of the test.

Results:
Phase 1: According to the Szigrist formula, the text was legible. After reverse translation, it was needed to clarify the terms between sickness and illness. The result was the securing of the Spanish version of the PPSv2.
Phase 2: The Test-retest was measured on days 0 and 2 and an ICC=0.89(0.69-0.96) was obtained.

Conclusion: The Spanish PPSv2 is a valid and reliable tool for measuring the performance status of patients receiving palliative care. Further studies are being carried out to demonstrate Spanish PPSv2 utility in daily clinical practice with a greater number of patients and health professionals.

Understanding Place of Death for Patients with Non Malignant Conditions

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Understanding factors influencing place of death is essential to achieve cost-effective, high quality care. Evidence on this has been reported in cancer, but not non-malignant conditions.

Aim: To systematically identify, appraise and synthesize the evidence on factors influencing place of death in advanced non-malignant conditions.

Methods: Qualitative/quantitative evidence was identified, extracted, quality-assessed, and synthesized.

Results: 290 included studies are heterogeneous in methods, populations, and quality. 17 studies (of 9,495 participants, 8 countries) reported evidence on place of death preference; mean prevalence of home death preference (weighted by study size) is 42%. 110 studies (of > 6 million participants, 12 countries) reported evidence on other factors affecting place of death. Considerations of family burden are a major influence. Higher levels of co-morbidity reduce odds of home death, but longer illness trajectories increase likelihood of home death. Increased hospital bed availability is consistently associated with greater odds of hospital death, and increased palliative care provision reduces odds of hospital death. The evidence on place of death is synthesized and a model of factors affecting place of death provided. Implications include:
1) home is sometimes, but not always, preferred place of death in non cancer;
2) effective carer support, especially with longer illnesses trajectories, may increase home death rates;
3) a smaller proportion of those with lower socio-economic status achieve home death; initiatives need to target this,
4) for older people, advance care planning is important, as their preferences are complex, highly dependent on circumstances and evolve over time.

Conclusion: The increasing ageing population, with higher co-morbidity, mitigates against home and for hospital deaths; innovative approaches must be developed to support those with complex co-morbidities in the community.

Funders: NIHR SDO (08/1813/257).
End-of-life care I

Abstract number: OA30
Abstract type: Oral

Factors Associated with the Priorities for Treatment and Care if Faced with Advanced Cancer Across Seven European Countries

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Aim: To examine variations in European citizens’ priorities if faced with terminal cancer, and identify influencing factors.

Methods: Telephone survey of a random sample of citizens aged ≥16 years in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. We asked respondents their priorities if ‘faced with a serious illness, like cancer, with limited time to live’. We used univariable then multivariable ordinal logistic regressions.

Findings: 9344 individuals were interviewed. 10% reported being seriously ill in the last 5 years. 65% (95% Confidence Interval (CI) 63-68) said that it would be more important to improve quality of life for the time they had left; 32% (CI 30-35) that quality and extending life were equally important and 2% (CI 1-3) that extending life was most important. Those who prioritised quality of life were also more likely to rank as most important having pain and discomfort relieved (38 v 29%, p< 0.0005). Multivariable analysis of data from all countries showed country was an independent predictor of choosing quality of life (p< 0.001, Wald X2=166.7, df=6); Spain was highest, 81% (CI 79-83). In all countries longer education was independently associated with choosing quality of life (OR ranged 1.3 England, 7.9 Italy). Other independent factors varied between countries but commonly included: age, gender, religion, financial hardship, having been involved in caring for a close relative/friend and having experienced the death of a close relative/friend in last 5 years. Health status did not affect preferences.

Conclusion: In all countries, when faced with advanced cancer, extending life is least important, and around two thirds choose quality of life. Cancer treatment and care should address top priorities including, providing information, dying in place of choice, symptom relief, supporting relatives/friends. The associations between priorities and demographic factors will help clinicians tailor care for individuals.

Abstract number: OA31
Abstract type: Oral

A Descriptive Study of Medical Interventions during the Last Stay in Cancer Patients who Died in Hospital

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Background: It has been claimed that the aggressiveness of cancer therapy has increased in end-of-life (EOL) care. Aim was to examine treatment given during the last inpatient stay of all cancer patients who died at the Department of Oncology in 2009 (45 beds), and compare results with data obtained 10 years back.

Methods: Data were retrieved from hospital records and the National database of population statistics. A retrospective chart review was performed for detailed registrations of the most common procedures (chemo/radiotherapy, surgery, symptomatic treatment etc.) in the last stay.

Results: 136 patients (M: 48%/F: 52%) with a median age of 68 (32-98) died in 2009, 32% in the palliative care (PC) unit. 58% were admitted from home, 16 and 11% from within-hospital out-patient clinics or other departments, respectively. Most prevalent diagnoses were gastro-intestinal (34 patients) and lung (21) cancer. 88% had metastatic disease. Median length of stay was 8.5 days (0-64), vs. 10.5 days in 1999. Four patients died at the day of admission. 16% received chemotherapy (7.7% in 1999), and median no. of days from start of chemotherapy to death was 22 days (13 in 1999), 24% received radiotherapy (9.6 % in 1999) at a median of 7 days before death. Only 2 patients received single fraction therapy. Nine patients spent time in the ICU during last stay. CT scans or MRIs were performed in 46 and 15%, respectively. Hydration, antibiotics and analgesic therapy were the most frequent interventions at both times. ESAS was the only standardized assessment tool used, almost exclusively in patients in the palliative care program (17/23).

Conclusion: Unfortunately, the use of systematic assessment tools is almost non-existent outside the PC program, and referral to specialized PC is unsystematic, also within the hospital setting. Our single centre-study cannot
Conclude that treatment aggressiveness in EOL has increased over time. More detailed assessment on the given therapy is necessary.

Abstract number: OA32
Abstract type: Oral

Palliative Sedation, Not Slow Euthanasia: A Prospective, Longitudinal Study of Sedation in Flemish Palliative Care Units
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Aims: Palliative sedation, as a therapy for refractory symptoms, remains a much debated and controversial issue both within and outside the palliative care movement. The diverse findings in current available literature, however, fail to answer ethical questions concerning this practice. The aim of this study is to describe the characteristics of patients who are being sedated for refractory symptoms in palliative care units from the time of admission until the day of death.

Methods: A prospective, longitudinal, descriptive design was used to assess data in eight PCUs. 266 patients were included in the study if they met the inclusion criteria and gave written informed consent. Information on demographics, medication, food and fluid intake, decision making, level of consciousness, and symptom experience were gathered by nurses and researchers three times a week. If patients received palliative sedation extra data were gathered on decisions making, refractory suffering, kind of sedation. Validity and reliability of used instruments was assessed in several pilot studies and proven useful for this patient population.

Results: 7.5% of the patients received palliative sedation. Sedation started, on average, 2.5 days before death and for half of these patients, the form of sedation changed over time. At the start of sedation, patients were in the end stage of their illness and needed total care. Patients were fully conscious and had very limited oral food and fluid intake. Only three patients received artificial fluids at the start of sedation. Patients reported, on average, two refractory symptoms, the most important ones being pain, fatigue, depression, drowsiness, and loss of well-being. In all cases, the patient gave consent to start palliative sedation because of increased suffering.

Conclusion: This prospective, longitudinal study has a significant added value and presents some interesting findings that need further examination in different patient populations.
Abstract number: OA34
Abstract type: Oral

Pattern of Hospital Admission in the Final Year of Life

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Aim: To study the pattern of hospital care people received in England 2004-08 in the final year of life. Numbers and proportions of admissions are reported by underlying cause of death, gender, age at death and deprivation quintile. Average numbers of admissions, bed days and length of stays are also reported.

Previous analyses have concentrated either on Office of National Statistics (ONS) mortality data or national Hospital Episode Statistics (HES) data.

Methods: Linked hospital records and individual death records have been analysed. The Office of National Statistics (ONS) and Hospital Episodes Statistics (HES) linkage provides a longitudinal view of the hospital services received 12 months before death. Using this linked data we have investigated the frequency, length and type of admission (elective, emergency) received. For the disease groups; cancer, cardiovascular disease (CVD), respiratory and stroke. This will inform policy around End of Life Care pathways and costing models for hospitals. The cohort includes individuals that died in England 2004-2008 and had at least one admission to hospital in the final year of life. We analysed how this varied with underlying cause of death, age, gender, deprivation and Local Authority (LA) of residence.

Results: We found that 78% of all ONS deaths had at least one hospital admission in the year before death; 88% of cancer deaths and 66% of CVD deaths had an admission. The average number of admissions a person will have in the final year of life is 3.5, this varies from Cancer deaths at 5.1 admissions to Stroke deaths with 2.3 admissions. The average number of bed days in the final year of life is 29.7; 36 days for stroke deaths and 18.1days for CVD. The average length of stay in the final year of life is 8.5days; 15.7days for stroke and 5.7days for Cancer deaths.

Conclusions: Hospital care at the end of life is important but the number of admissions and length of stay could be reduced.

Abstract number: OA35
Abstract type: Oral

Past and Future Trends in Place of Death in Belgium: A Shift from Hospital to Care Home Death

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Background: Since most patients prefer out-of-hospital death, place of death is considered an indicator of end-of-life care quality. Studying trends in place of death is necessary to examine causes, to evaluate efforts to alter place of death and develop future policies. This study aims to examine past trends and future projections in place of death.

Methods: Analysis of death certificates in Belgium (Flanders and Brussels Capital Region) 1998-2007. Trends in place of death were adjusted for cause of death, sociodemographic characteristics, environmental factors, number of hospital beds and residential and skilled nursing beds in care homes. Future trends were based on age- and sex-specific mortality projections.

Results: Hospital deaths decreased from 55.1% to 51.7% and care home deaths rose from 18.3% to 22.6%. The percentage of home deaths remained stable. Among care home residents, hospital deaths decreased from 31.0% to 21.5%. The adjusted odds ratio of care home residents of dying in the care home of residence versus in hospital increased steadily over the years and was 1.65 (95%CI:1.53-1.78) in 2007 compared to 1997. This increase could partially be attributed to the replacement of residential beds by skilled nursing beds. Deaths of people living at home and dying in care homes and of people living in care homes and dying at home increased substantially. The adjusted odds ratio of people living at home of dying at home versus in hospital did not increase over the studied ten year period. Continuation of these trends would result in the more than doubling of deaths in care homes and a decrease in deaths at home and in hospital by 2040.

Discussion: Additional skilled end-of-life care resources in care homes largely explained the decrease in hospital deaths. Care homes may become the main locus of end-of-life care homes largely explained the decrease in hospital deaths. Care homes may become the main locus of end-of-life care in the future. Governments should provide sufficient skilled nursing resources in care homes to fulfill the end-of-life care preferences and needs of patients.

Research in action: from policy to practice and back

Abstract number: INV15
Abstract type: Invited Speaker

Addressing the Complexity of Policy Implementation: Evaluations of the National End of Life Care Programme

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The National End of Life Care Programme is a service and practice-development initiative to improve equity of access and quality of end of life care for all adults. It supports local innovation. Its early work influenced the development of the first End of Life Care Strategy for England (2008); it has subsequently been responsible for implementation of the Strategy.

**Aims:** To evaluate the process, sustainability and impact of the programme in terms of its intended and achieved outcomes relating to quality end of life care.

**Methods:** A pragmatic evaluation approach was employed to study the first (2004-7) and second (2008-11) phases of the Programme involving 3 elements: (a) qualitative interviews with stakeholders (n=57); (b) documentary analyses to study variations in uptake of recommended end of life tools and use of Programme publications; (c) locality based case studies to investigate practice, with an emphasis on end of life care planning, including an audit of care provided to a random sample decedents over one year (n=65) and seven focus groups with health and social care staff (n=42).

**Findings:** Stakeholders perceived that the Programme had been critical in the development and implementation of the End of Life Care Strategy. Factors seen as integral to the successful roll out of the Strategy included perceptions that the Programme staff team were flexible, accessible, responsive and dynamic leaders. Documentary analyses showed great regional variation in tool uptake. Extensive dissemination of educational materials had occurred. Locality based case studies showed that much work remains to be done to embed principles of end of life care planning in practice.

**Conclusion:** The impact and outcomes of the Programme are indivisible from the processes and style of the working practices of Programme staff; impact and outcome must be linked to the activities and changes occurring at local levels for which the Programme is a catalyst.

**Abstract number:** INV16  
**Abstract type:** Invited Speaker

**Research into Practice in the USA: Emotive and Misleading or Good Science**

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Recent highly publicized controversies surrounding the translation of evidence-based research into public policy in the United States (e.g, mammography screening for breast cancer, PSA screening for prostate cancer) have focused attention on the complex interaction of biomedical research, scientific uncertainty, human emotion, and professional and public opinion on the development of sound public healthcare policy. In this session, we will explore why good science is necessary, but not sufficient to inform good public policy. Specifically, we will use palliative as an example as to how knowledge about public opinion, political realities, and social change theory can are necessary in order to transform sound scientific research into effective public policy both in the United States and in other countries.

**Abstract number:** INV17  
**Abstract type:** Invited Speaker

**Changing Medication Access Policy in Eastern Europe: State of Confusion?**

**Mosoiu D.**  
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A challenge encountered by palliative care professionals in Eastern Europe is the impossibility of applying up to date knowledge in pain management in their own setting due to a variety of reasons: low availability of strong opioids usually just injectable morphine and meperidine, lack of availability of oral morphine in the country (most ex-soviet countries), restrictive policies (in terms of patients categories that are allowed to receive the strong pain relief medication, maximum daily dose, number of days per prescription, signatures and authorization required), fears and preconceptions existing in the population and health care professionals, low priority given to pain management in the basic and postgraduate training programs, health care systems focused on acute care and not the last the different meaning associated to suffering and pain compared with western cultures.

The confusion comes together with import of foreign policies through a top down decisions, with little consultation and technical support or thorough follow up and implementation plans. Also when radical changes in the policies are coming in contradiction with deeply rooted habits that have abruptly to be replaced with new ways of acting there is not just fear, resistance in applying new legal provisions but also risk of misinterpretation. Romania’s uptake of new opioid policy will be analysed.

Joint European projects like ATOME (access to opioid medication in Europe) by bringing together in international workshops and follow up national conferences policy makers and palliative care experts is creating a platform for better understanding of perspectives and problems in the 12 target countries of the project and is fostering change.

**Symptoms other than pain II**

**Abstract number:** OA36  
**Abstract type:** Oral

**Can Depression Be Used as a Prognostic Factor in Palliative Care?**
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**Background/aims:** Depression is known to be a common symptom in advanced cancer and the difficulty of assessment and treatment are widely known. This paper reports a prospective study of ambulatory palliative care patients to determine the impact of depression on survival and whether depression is an independent prognostic factor for survival.

**Methods:** Patients with an estimated prognosis of 6 months or more were recruited from palliative day care units and assessments carried out at baseline, 2, 4 and 6 months. Assessments included demographic data, Edinburgh Depression Scale, Demoralisation Scale, Beliefs and Values Scale, Symptom scores and PHQ9.

**Results:** Six hundred and twenty-nine patients were recruited into the study; age range 21-93 years mean age 66 years, 67% were female and 75% had an ECOG performance score of 1 or 2 at study entry. Median Survival of all patients in study was 37.1 weeks (range 0 weeks - alive at end of study period); 125 patients died during follow up and 221 died in total during the study period (November 2007- February 2010). At baseline 34% of patients reported previous episodes of depression and depression as measured by PHQ9 was measured as moderate or severe in 33% of patients at baseline. The risk of death when controlled for all other factors was 1.3 times higher for patients with a PHQ9 score of 9 or more (indicative of moderate to severe depression) at baseline. The median survival time of patients whose baseline PHQ9≥9 was 36 weeks (95% CI 31, 39 weeks) and that for patients whose baseline PHQ9<9 was 39 weeks (95% CI 37, 45 weeks) p = 0.033.

**Discussion:** This large longitudinal study of patients with advanced cancer suggests that depression is an independent prognostic risk factor for early death. It is important to assess and treat depression in late stage cancer as it is to assess and treat all other symptoms.

**Abstract number:** OA37

**Abstract type:** Oral

**Depressed Cancer Patients with Advanced Disease - Which Depressive Symptoms Do they Experience?**

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**Aims:** Diagnosing depressive disorders is based upon psychiatric classification systems. The overlap between some diagnostic criteria for depressive disorders and cancer-related symptoms is a challenge in palliative care. As a contribution to developing a future classification system for depression in palliative care, depressive symptoms experienced by palliative care cancer patients were explored.

**Method:** Advanced cancer patients taking antidepressants for a depressive disorder, were included. Semi-structured interviews on symptom experience were transcribed verbatim. By the phenomenographic method, categories of symptoms of major depressive disorder were extracted and sorted under headings, first individually and then across patients.

**Results:** Thirty patients were included (Norwegian n=20, Austrian n=10). Depressive symptoms reported consistently could be grouped under the following headings; depressed mood/sadness, diminished motivation/feeling inhibited, despair, social withdrawal, a relentless focus on their present situation, disrupted sleep, anxiety and restlessness. Depressed mood/sadness, diminished motivation/feeling inhibited, a relentless focus on the present situation, disrupted sleep and restlessness resemble the diagnostic criteria. Appetite and weight changes were not restricted to the depressive period. Diagnostic criteria as psychomotor retardation, feelings of worthlessness or excessive or inappropriate guilt and recurrent suicidal ideation were not reported consistently. Symptoms reported as alternatives to the psychiatric criteria were despair, anxiety and social withdrawal.

**Conclusion:** A future classification system for depressive disorders may include adjustments of existing diagnostic criteria. The appropriateness of diagnostic criteria can be enhanced by modification of some criteria and supplemented by symptoms on despair, anxiety and social withdrawal. Some diagnostic criteria seem less appropriate in the palliative care setting.

**Abstract number:** OA38

**Abstract type:** Oral

**Symptoms in Children with Rare Life-limiting Conditions: Methodological and Substantive Findings from a Prospective Mixed-method Study**
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Despite symptoms being a key concern, their assessment and management in palliative care for children remains largely unexplored. This study aimed to document the symptom profile of children with rare life-limiting conditions and family experiences of providing symptom support.

26 children and their families were recruited from children’s hospices across the UK. All children had a diagnosis of either Mucopolysaccharidosis or Batten disease. These life-limiting conditions are characterised by progressive and permanent loss of physical and cognitive function.

Families completed a daily symptom diary for eight weeks to document the frequency, severity and management of their child’s symptoms. Following diary completion, qualitative interviews were conducted with parents, siblings and practitioners to explore the wider issues of supporting the child and managing symptoms. Study design was informed by an understanding of symptoms as multifactorial. Systems theory provided the overarching framework for data interpretation. Descriptive statistics and grounded theory guided data analysis.

Diary data highlighted that behavioural symptoms (agitation, repetitive behaviours and hyperactivity) occurred frequently, and were experienced as both severe and difficult to manage. This stands in stark contrast to the usual emphasis on pain and seizures as main symptoms of concern. Interview data revealed that it was the meaning associated with the symptoms which was most significant to families, in signalling decline and ultimate death. Clinical implications, generated through these mixed methods, suggest a need to prioritise the impact and meaning of behavioural symptoms on the child and family.

Parents considered the diary to be both an acceptable research tool and a communication aid to facilitate discussion regarding symptoms, indicating fruitfulness for clinical and methodological advances in paediatric palliative care.

Abstract number: OA39
Abstract type: Oral

The Physical Functioning of Women with Advanced Breast Cancer Treated with Chemotherapy

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Aim: The present study is a prospective observation study evaluating the functional capacity of 128 out of 211 women with advanced breast cancer during the chemotherapy treatment at the Helsinki University Hospital, Department of Oncology in year 2009 (recruitment rate 61%).

Methods: The static balance was tested using one foot stance, the strength of lower extremities with a five times sit-to-stand test and a test of repeated squatting, functional exercise capacity with 6-minute walking distance. Functioning of upper extremities was evaluated with shoulder movement and by the grip strength. QoL was tested by EORTC-QOL-C30 and SF36, and depression by RBDI questionnaires.

Results: The mean age was 60 years (34-84). The mean intensity of pain (NRS 0-10) was 3.9 (SD 2.9) and disability caused by pain 4.44 (SD 3.2). 37.0% were depressed by RBDI. Dynamic balance was normal in 28 (21.9%) and below the normal in 45 (49.5%), static balance (91 women aged < 60 years) in 100 (78.1%) and 46 (50.5%), 6-minute walking distance in 55 (43%) and 73 (57%), muscle strength of lower extremities i.e. repeated squat (44 women aged ≤55 years) in 12 (27.3%) and 65 (69.9%) and sit-to-stand test (93 women aged ≥55 years) in 32 (72.7%) and 28 (30.1%), grip strength of right upper extremity in 72 (56.2%) and 89 (69.5%), and left in 56 (43.8%) and 39 (30.5%), shoulder movement in 90 (70.3%) and 38 (29.7%), respectively. Depression [0.66 (0.55 to 0.78), p < 0.001], pain [0.62 (0.52 to 0.74), p < 0.001], sit-to-stand test time [3.72 (1.37 to 10.07), p = 0.010], 6-m walking time [3.38 (1.24 to 9.19), p = 0.017] and age [0.95 (0.91 to 0.99), p = 0.016] were the most important determinants of physical component (SF36) in logistic regression analyses.

Conclusions: Breast cancer patients with advanced disease have poor physical performance, especially muscle strength of lower extremities and balance, which correlated to poor physical functioning, together with age, depression and pain.

Abstract number: OA40
Abstract type: Oral

The Psychometric Properties of Cancer Multisymptom Assessment Instruments: A Clinical Review

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Objectives: Symptom research requires data from valid, reliable instruments. We evaluated the characteristics of cancer multisymptom assessment instruments to determine their psychometric quality.
For the treatment of fatigue there is still no consensus on treatment guidelines. However, beside non-pharmacological treatments, anti-depressants, corticosteroids, and psycho-stimulants have been advocated. Modafinil is a central nervous system stimulant and may be an option in tumor-related fatigue.

The aim of this study was to assess the efficacy of modafinil (200 mg and 400 mg) in the treatment of fatigue in cancer patients in a palliative care setting. In addition, side effects of modafinil were to be assessed.

A randomised, double-blind placebo-controlled study with multiple cross-over was conducted between March 2006 and December 2007. A total of 24 patients from the Department of Palliative Medicine at the University Hospital Aachen were included. Eighteen patients completed the study period of 12 days (four phases of three days). The primary outcome was the score of fatigue in the MIDOS-questionnaire (Minimales Dokumentationssystem).

Although the results did not show a statistically significant reduction in the mean of fatigue-scores on the modafinil treatment in the current study, it is worthwhile mentioning that in 3 patients modafinil treatment had shown the desired benefit (responders). At the end of the trial 75 % of patients with 200 mg chose to continue modafinil treatment. Modafinil was related to an improvement of cognitive function and well-being, specially with 200 mg.

Regarding side-effects there was no difference between patients receiving modafinil versus those with placebo.

The study showed a lack of efficacy of modafinil in the average fatigue scores, but an adequate response in a small subgroup of patients. The percentage of responders should be evaluated in larger scale follow-up studies.
Background: Carrying out statistical analysis in P&EoLC research can be problematic due to high levels of missing data and attrition as patients’ disease progresses.

Methods: We used the MORECare Transparent Expert Consultation approach to conduct consultation workshops with experts in statistical methods in P&EoLC research. Prior to workshops participants were sent overviews of pertinent issues in statistical methods in P&EoLC. Following workshop presentations and discussion, nominal group techniques were used to produce candidate recommendations. These were subsequently rated online by participating experts. Descriptive statistics were employed to permit analysis of consensus and rated importance. Narrative comments were collated.

Results: The statistical methods expert workshop comprised 20 participants making 19 recommendations. There was broad agreement across most recommendations, the top 5 recommendations were:

1. Types and amount of missing data should be reported along with imputation methods.
2. Pattern of missing data should be investigated to inform imputation method.
3. A statistical analysis plan should be in place.
4. A taxonomy should be devised to define types of attrition.
5. Use of transition questions and minimally important difference approach provides insight into response shift.

Conclusions: When designing studies in P&EoLC it is recommended that high rates of attrition should not be seen as indicative of poor design and that a clear statistical analysis plan is in place to account for missing data and attrition. More research is required in statistical methods to assess these areas but also develop the emerging area of response shift.

Abstract number: OA43
Abstract type: Oral

Quality of Reporting of the Palliative Cancer Care Literature

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Aims: The quality of the palliative care literature is unclear. In this study, we examined and compared 5 indicators of study quality in the palliative cancer care literature published in the first 6 months of 2004 and 2009.

Methods: We systematically searched MEDLINE, PsycInfo, EMBASE, ISI Web of Science, and CINAHL for original studies related to “palliative care” and “cancer” during the first 6 months of 2004 and 2009. For each study, we extracted the study size, the sample size calculation and other study characteristics. We also determined the CONSORT overall quality score, the key methodologic index and the Jadad score for randomized controlled trials (RCTs).

Results: A total of 840 studies were included for sample size analysis, and 44 RCTs were identified for quality of reporting analysis. The median sample size was 70 for RCTs, 112 for cohort studies, and 200 for cross sectional studies. Sample size calculations were most frequently reported in RCTs; however, 29/44 (66%) RCTs had no reporting, 5/44 (11%) had partial reporting, and 10/44 (23%) had full reporting. The median CONSORT overall quality score was 9 (interquartile range 7-11), key methodologic index was 0.50 (interquartile range 0-1.75), and Jadad score was 2 (interquartile range 1-3), suggesting low quality of reporting. We found no differences in the quality scores between 2004 and 2009. Key methodologic index score >=2 was associated with the presence of funding from any source (10/25 vs. 1/19, P=0.013) and funding from pharmaceutical industry (5/9 vs. 6/35, P=0.03).

Conclusions: Most studies were small and had inadequate reporting of sample size calculations. RCTs in palliative cancer care were few in number and had significant deficiencies in the reporting quality. Studies with higher key methodologic index were more likely to be funded. Further efforts are needed to improve funding, training of investigators, and journal reporting standards.

Abstract number: OA44
Abstract type: Oral

Why Bereaved Relatives Refuse Research Participation: Results from a Cancer Mortality Followback Survey

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Aims: To examine reasons for refusal to complete a followback survey in the first year of bereavement.

Methods: A mortality followback survey, 920 relatives of cancer patients from a sample of 1516 identified from death registrations in four health regions in London (UK) who did not return a postal questionnaire about end of life care (sent 4-10 months after death registration). Refusal reasons volunteered by non-respondents (through reply slips, letters and calls) were analysed line-by-line using content analysis. Two independent raters applied an agreed inductive coding frame to all data (kappa statistic measured agreement) with disagreements solved by consensus.

Results: Out of 920 non-respondents, 58.9% did not contact the research team (‘silent refusals’); 0.5% were unreachable/moved away, 3.0% expressed willingness but did not return the questionnaire; 37.6% actively refused. 59.2% of these (n=205) justified their decision (36.6% with...


C.1, Watanabe S.1, Quan H.2

pain. 126 of 816 patients had normal cognition, no unique patients, with 816/3646 (22%) having neuropathic intensity >4/10, and location of care. Fifty people commented on care (comments were good for 32, bad for 7 and both good and bad for 11). Raters coding agreement was high (kappa=0.85, 95% CI 0.71 to 0.98).

Conclusion: Grief is a frequent reason for refusing research participation in the first year of bereavement; studies and questionnaires therefore need to be sensitively designed. Further, even carefully designed questionnaires are not able to cover all care experiences. Identifying respondents via death registrations has limitations; not all know enough about care received. Analysis of socio-demographic data may help understand ‘silent refusals’ and identify profiles of those for whom grieving influences participation. Funded by Cicely Saunders International.

Abstract number: OA45
Abstract type: Oral

Using a Comprehensive Palliative Care Program Database to Plan Research Trials in Palliative Care

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Aims: Our Zone Palliative Care Program (ZPCP) has a comprehensive integrated service delivery model that provides 24-hour 365 day palliative care consultation services to all acute, community and rural locations in the health care zone. There are also 20 beds in a Tertiary Palliative Care Unit (TPCU). Standardized assessments are used in all locations of care. Patient data including assessments are entered into an electronic database. A recent multi-site study illustrated the role of consecutive cohort audits for planning clinical research. The aim of this study was to assess the feasibility of using our database to identify potential participant sites and recruitment times for clinical research, instead of more time consuming audits.

Methods: We performed a prospective mixed-methods observational study of the care given to patients who were dying in hospital. All patients on five study wards were screened on admission using the question, ‘Is this patient so unwell you feel they could die on this admission?’ If the answer was ‘yes’ the patient (and/or family) was approached to give prior consent to being included in the study ‘should they become more unwell’. We calculated the sensitivity and specificity of the screening question and the proportion of patients providing consent.

Results: Over two years, 6703 patients were screened; staff answered ‘yes’ to the screening question for 327 patients (5%). The screening question had a sensitivity of 57% and a specificity of 98%. Prior consent (23) or relative assent (94) was obtained for 117 (36%) of these patients. 70 died within the study. Only 25 (7%) patients were considered too distressed to approach and only 17 (5%) declined to participate. Other reasons for non-participation included patient improvement (53), death very soon after screening (45) and logistical reasons e.g. patient moved to a non-study ward.

Conclusion: To our knowledge prior consent for research during the dying process has not been used before within an acute trust. Whilst a large number of patients were screened,
our screening question was helpful in identifying patients who could die during an admission. It was possible to gain consent from about a third of these patients, or assent from their relatives, for inclusion in a study to examine their end-of-life care.

Abstract number: OA47
Abstract type: Oral

MoreCare Research Methods Guidance Development: Recommendations for Using Mixed Methods to Develop and Evaluate Complex Interventions in Palliative and End of Life Care

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Aims: Mixed method research is valuable for complex intervention development and evaluation in palliative and end of life care (P&EoLC) yet we lack guidance on addressing the challenges of using it in this field. Thus we sought to identify agreed best practice.

Methods: We used the MORECare Transparent Expert Consultation approach in a workshop with literature-identified experts in mixed methods and P&EoLC research. Delegates (n=33) heard overviews of challenges in mixed methods and P&EoLC research. Following discussion, nominal group techniques produced candidate recommendations which were de-duplicated and synthesised into 9 draft recommendations. These were rated online by workshop delegates and MORECare advisory group. Descriptive statistics analysed agreement ratings. Narrative comments were collected.

Results: Highest agreement was with the need to consider respondent burden given the population in P&EoLC. Mixed method research was recommended as useful given P&EoLC’s outcome measurement challenges. It was recommended that trial registers include qualitative component fields and that implementation studies be encouraged. Further, multi-disciplinary research teams were recommended and qualitative exploration of respondent participation experience given the relative infancy of P&EoLC research. The need for researcher skill-sets addressing both mixed method needs and P&EoLC sensitivities was acknowledged. Awareness of potential therapeutic effects (contamination) from research interviews in intervention trials was important, as was consideration of theoretical perspectives from the outset.

Conclusions: This is the first attempt to produce guidance on mixed methods that addresses challenges P&EoLC research can present. When designing studies researchers should consider the expert recommendations. Publication of these recommendations may encourage uptake and advance appropriate use of mixed methods in the field.

Palliative sedation: state of the art research findings

Abstract number: INV18
Abstract type: Invited Speaker

Clinical and Epidemiological Research in Palliative Sedation: How Has It Served Physicians till Now and What Should We Expect for the Future. A Review of the Literature

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Extensive research on sedation in palliative care has been conducted during the last 20 years. Meanwhile, clinical guidelines have been published worldwide. In 2009 the EAPC offered a recommended framework for sedation in palliative care, after prolonged consultation among clinicians and other experts. The framework helps to focus important clinical aspects of sedation in palliative care, taking into account a lot of clinical variability and adopting a multidisciplinary perspective. We wondered whether epidemiological and clinical research was attuned with this framework, in order to have results more likely to help physicians and nurses in their daily work.

A systematic review was conducted to investigate the issue, searching on PubMed at November 2011 among papers published in English from 1990. Among the 769 abstracts collected 307 dealt with control of pain in various medical procedures, with non-refractory symptoms, with issues specific to Intensive Care Units or to paediatric age. Other 298 abstracts did not report primary data. 40 of the remaining papers used qualitative methods only. 124 abstracts were considered for the systematic review of medical studies reporting primary data on sedation in palliative care, excluding specific care settings like paediatric and intensive care. 79 of the papers focused on practices and will be presented in this contribution. The remaining 45 concerned attitudes towards sedation in palliative care and will be presented successively. Four clinicians, one statistician and one
Aim: 

The aim of this study was to investigate nurses' beliefs, attitudes, and behaviors in palliative sedation, and to explore their experiences in the use of sedation for symptom management in end-of-life care for cancer patients. The study involved focus groups with nurses from specialist and non-specialist nursing teams. The nurses were drawn from hospice, hospital specialist, palliative care, acute hospital practice, community specialist, and non-specialist nursing teams. Data were analysed using NVivo, taking a constant comparison approach. The findings showed that nurses understood sedation as symptom management and 'comfort' therapy for the relief of anxiety and distress. Practice was described as beginning with single 'as required' doses, which progressed to continuous sedation as the number of single doses increased. Continuous deep sedation for refractory symptoms was described as a rare experience. Decision making was perceived to be a team activity. Where patients lacked capacity, nurses made decisions in the light of family concerns. Barriers to sedation practice included negative attitudes of other staff and patients' families and a desire not to be thought to be hastening death. Facilitators included health professionals' experience in the use of sedation, 'knowing' the patient and levels of trust between nurses, other health professionals, patients, and family carers.

Conclusion: 

These findings draw attention to key roles nurses have in decision making implementation and monitoring of continuous sedation.
**Background and aim:** Computers may facilitate communication between health care personnel and patients by providing a direct channel not relying on physical proximity. However, this depends on the patients being able to use and understand the computer program. We wanted to investigate factors of importance to make a computerized assessment tool suitable for palliative care cancer patients.

**Method:** The research question (title) was investigated by use of a computerized pain body map on a tablet PC with a touch sensitive screen. Patients were asked to mark the location and intensity of their pain on the body map while using the think-aloud technique. Their verbal statements were tape recorded and a video recording of the screen was made. The patients were also interviewed about the usability of the program. Combining interview, observations and recordings showed which parts of the program the patients were able to understand and manage, and where they had difficulties.

**Results:** Nine (M:5/F:4) patients with advanced cancer and varying computer experience were included, mean age 60 (47-75), ECOG status 2 (0-3), and mean MMSE 29 (26-30). All patients were able to use the program, but were dependent on clear instructions and feedback from the computer. They were confused by quick screen changes and by having to remember their own input from one screen to the next. They needed simple and clear instructions to be able to redo or adjust their input. Ergonomics were challenging, especially to combine a good view of the screen with necessary support for the arm in bedridden patients.

**Conclusion:** A computerized tool for palliative care cancer patients must be simple, with large fonts, unambiguous instructions and clear, direct feedback confirming the patients’ selections and allowing them to track their input and understand the logic of the program. Quick changes must be avoided. To allow use by bedridden patients, the equipment must have a high focus on ergonomics.

**Abstract number:** OA50
**Abstract type:** Oral

**The Prognostic Impact of Palliative Performance Scale Score Decline for Hospital Palliative Care Cancer Patients**

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Recently a large retrospective study has suggested that an abrupt decline in Palliative Performance Scale (PPSv2) scores represents a sentinel event for shorter survival. Despite these findings, data on the prognostic impact of PPS score changes are scarce.

**Aims:** To analyze the prognostic meaning of PPS changes on two consecutive evaluations.

**Methods:** We prospectively followed all cancer patients enrolled in a hospital-based palliative care program for a 9-month period. Patient characteristics (age, gender,
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Diagnosis, current anticancer treatment, location) as well as PPS, palliative care phase and conscience level on admission, and then, on each visit, were recorded. Kaplan-Meier curves were used to compare the survival of patients admitted with a given PPS who experienced a functional decline (FD - i.e. a drop of at least 10% on PPS) on visit 2.

**Results:** Our 239 patients’ cohort (median age 67, 48% male, 50% digestive tumors, 45% under cancer treatment, 63% outpatients) had median initial PPS of 40 and overall length of stay in program of 46 days. Forty-six (19%) were discharged to other settings and 32 (13%) died before visit 2. A median of 7 days (range 2-20) elapsed between admission and visit 2. Twenty-eight per cent (45/161) experienced a functional decline (29, 13 and 3 had PPS drops of, respectively 10%, 20% and ≥30%). Delirium at admission was the only predictor for FD (OR 2.6 p=0.02). At both points the lower the PPS the shorter the survival. FD on visit 2 was associated with shorter survival [median 28 days (95%CI 12-45) vs. 94 days (95%CI 58-130) p<0.001)]. For patients admitted with PPS ≤50 the magnitude of PPS drop was significantly predictive of a shorter survival probability. The survival of patients with a 10% PPS drop on visit 2 was comparable to patients who were admitted at the lower “dropped-to” PPS.

**Conclusion:** PPS drop monitoring can add relevant information to assist prognostic discussions with patients and families and planning care.

**Abstract number:** OA51
**Abstract type:** Oral

**NeuPSIG Criteria in Neuropathic Cancer Pain (NCP)**

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**Background:** Pain in cancer patients is often inadequately treated. This may be because neuropathic pain mechanisms are not identified. Recent NeuPSIG guidance proposed standardised assessment criteria for neuropathic pain in which at least 3 of the following 4 criteria need to be met for diagnosis: neuroanatomical pain distribution, history of relevant lesion, confirmed neurological abnormality on examination, confirmed neurological lesion on diagnostic testing. We examined how these 4 criteria were applied in studies of NCP.

**Method:** We searched Medline, Embase and Cochrane. Articles were included if they were clinical trials or prevalence studies that recruited patients with advanced cancer and pain, and when assessment of pain type was made by a clinician. Studies about acute neuropathic pain related to cancer treatment, exclusively due to infections, or reviews and abstracts were excluded.

**Results:** 31 papers were found, 9 RCTs and 22 prevalence studies which reported on 13912 patients. Criteria 1, 2, 3, and 4 were met in 19, 22, 20, and 12 studies, respectively. 15/31 studies reached a probable or definite grading of NCP (7/9 RCTs and 8/22 prevalence studies) based on NeuPSIG criteria. Of these, 14 confirmed neurological dysfunction using bedside testing and 1 used diagnostic testing to identify a neurological lesion. The most frequently used criteria were 2 combined with 3. In 8 studies with more reliable diagnoses (probable or definite), prevalence estimates were lower than in studies with less reliable diagnoses.

**Conclusions:** A reliable diagnosis of NCP was found in only half of the included studies. Criterion 4 was used less than other criteria. In cancer pain where mixed mechanisms commonly exist, we believe that establishing neurological dysfunction (using bedside testing) is more important as a confirmatory test than diagnostic imaging. We propose that NeuPSIG criteria 1-3 be used to establish the presence of NCP.

**Abstract number:** OA52
**Abstract type:** Oral

**The Influence of Disease Burden on Measures of Depression in Cancer Patients with Advanced Disease**

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**Aims:** Diagnosing depression in patients with cancer can be problematic because of the potential overlap of cancer
and depression symptoms. Yet the severity of the cancer, affecting the potential for symptom overlap, is rarely considered. We studied the prevalence rates of major depressive disorder (MDD) defined in three different ways, as well as the relationships between MDD, depressive symptoms and disease burden in cancer patients with advanced disease.

**Methods:** 1070 cancer patients from eight countries were recruited in a large multi-centre study, the EPCRC-CSA, in 2008-2009. Depression was assessed by the PHQ-9 self-report questionnaire. MDD was defined by the DSM-IV-based scoring algorithm (9 symptoms), a modified DSM-IV-based algorithm (5 symptoms) and as a sum score using cut-off scores. Measures of disease burden, including biomarkers: CRP, albumin and haemoglobin levels, were retrieved from patient records.

**Results:** Including or excluding somatic symptoms when measuring MDD using DSM-IV-based scoring-algorithms had little effect on prevalence rates, 13.7% and 14.9% respectively (Kappa = 0.81). However, the continuous scoring method with cut-off scores recommended for cancer patients yielded prevalence rates of >31%. Higher disease burden predicted MDD regardless of which MDD definition was used, also when excluding the somatic symptoms. Moreover, various measures of disease burden predicted both somatic and psychological depressive symptoms.

**Conclusion:** Although both depressive disorder and symptoms seemed to co-occur with disease burden, including or excluding somatic depressive symptoms did not influence MDD prevalence rates when using DSM-IV-based scoring-algorithms. The continuous-scoring method, however, appeared to result in a large increase in the number of false positive cases. Thus, it is important to be aware that disease burden can in some cases have different effects on the measurements and hence the outcomes.

**Abstract number:** OA53  
**Abstract type:** Oral  
**Feasibility and Acceptance of Electronic Monitoring of Symptoms and Syndromes Associated with Cancer in Daily Oncology Practice Using a Handheld Computer (E-MOSAIc)**

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*Walker J.*,  
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In patients (pts) with advanced cancer pain, other symptoms and nutritional problems are often underestimated due to poor detection. The clinical benefit of anticancer treatments is rarely monitored. Electronic monitoring is only effective if perceived useful by pts and health care professionals. We investigate the feasibility and acceptance of electronic monitoring of symptoms and syndromes associated with cancer in daily oncology practice using a palm (handheld computer).

**First part:** Symptomatic pts with advanced cancer completed an ESAS and the physician completed monitoring sheets with 4 pairs of defined symptoms and syndromes. The compliance and experiences were assessed. Based on the experiences we developed E-MOSAIC consisting of three elements: (1. ESAS, optional symptoms [0-3], estimated nutritional intake (NI), 2. body weight, KPS, 3. medications for pain [e.g., MEDD, NSAR], fatigue [e.g., methylphenidate], and cachexia [e.g., nutritional supplements, prokinetics]).

**Second part:** Pts completed E-MOSAIC in a paper-pen and a palm version. Preferences, experiences, perceived usefulness, time needed and test-retest reliability were assessed. A Wilcoxon-test was performed.

**First part:** 21/21 completed. Physicians perceived the assessment as useful in 17/21 and improvement clarity of goals of treatment in 20/21 cases.

**Second part:** 54 pts participated. 4 pts had visual, 6 comprehension problems and 1 was too tired. 3 did not complete. Median time was 3 minutes. 10 pts preferred paper, 28 palm, 16 no preference; Nurses preferred palm in 44 cases. 50 pts agreed to continue using palm. Wilcoxon-test confirmed no significant differences in ESAS (range 0.249 - .940), but in NI (0.013). Test-retest (1 hour, n=20) reliability was satisfactory (range 62 - .94).

Symptom and syndrome monitoring is feasible and perceived as useful in an oncology outpatient clinic. E-Mosaic by palm shows a high acceptance in pts and nurses. A large multicenter study is running.

**Cognitive impairment**

**Abstract number:** INV21  
**Abstract type:** Invited Speaker  
**How to Assess Cognitive Functioning in Advanced Disease? Cognitive Domains, Tools and Trials**

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**Aims:** Cognitive dysfunction is frequent in later stages of cancer disease; however, correct diagnosis is often missed. Review studies have been performed to analyze available tools to assess cognitive function and to identify key cognitive domains in cancer patients.
Methods: Two reviews were conducted and updated in 2011, in which cognitive assessment was analyzed in 2 selected cancer populations: patients receiving opioids in controlled trials (Review 1) and palliative care patients in different studies (Review 2). Reviews were performed according to Oxford Centre for Evidence-based Medicine recommendations. Inclusion and exclusion criteria were applied (dementia and delirium were excluded). Searches were performed on the main databases and included Pubmed, Embase and PsycInfo.

Results: Review 1: 590 abstracts, 11 studies were selected. 22 instruments were identified. Reaction Time (8/22), Finger Tapping (4/22), Digit Span (3/22) and Trail Making (2/22) were the most used instruments. The majority were oral or paper/pencil tests. Eight tools captured alterations and cognitive domains affected were memory, attention, psychomotor speed and planning abilities. Review 2: 468 abstracts, 24 were selected. 22 instruments identified. The Mini-mental State Examination-MMSE (9/22), Trail Making (7/22) and the Wechsler Adult Intelligence Scale (5/22) were most commonly used. The majority were paper/pencil or oral tests. Thirteen tools captured alterations and only MMSE was validated in cancer patients. Deficits in memory, executive function and fine motor coordination were most frequently reported.

Conclusion: Memory, attention, planning abilities, executive and psychomotor functions seem to be the key domains. However, there are few studies and a clear lack of validated instruments in cancer. Further trials should aim to determine validity, reliability and cut-off points based on sensibility and specificity of clinically relevant neuropsychological tests for this population.

Abstract number: INV22
Abstract type: Invited Speaker

The Cognitive Effects of Opioids

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Opioids are well known to influence cognitive functions in cancer pain patients. However, cognition may be impaired in cancer pain patients due to several other causes. Therefore, cognitive failure in patients receiving an opioid do not necessarily equals cognitive failure caused by opioids. The lecture will review current literature related to cognitive failure in patients treated with opioids.

Abstract number: INV23
Abstract type: Invited Speaker

The Cognitive Effects of Symptoms and Comorbidities in Advanced Cancer

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Aims: To describe the effect of different etiologies on the cognitive functions of patients with advanced cancer and the role of cognitive function failure in complicating symptom control at the end-of-life.

Methods: A review of the literature using delirium and cognitive failure as key words limited to articles including patients with advanced cancer undergoing palliative care.

Results: Clinically relevant effects on cognition in patients with advanced cancer are due to a complex multifactor etiology. Multifactor analyses identified bone, liver, brain metastases, use of higher doses of opioids and benzodiazepines as independent predictors of delirium in patients with cancer. Only a few specific studies addressed the impact of cognitive failure in patients with cancer undergoing palliative care. Symptoms, and pain in particular, are also known to affect cognitive functions but data from palliative care are very scarce in this area. Delirium is finally a common complication at the end-of-life and its treatment overlaps with the control of terminal symptoms.

In general the overall evidence from the literature confirms that cognition is compromised in the advanced phases of cancer by a combination of the effects of the disease, of its symptoms and of symptom treatments. The accurate assessment and diagnosis of cognitive functions should therefore be an integral part of any palliative care clinical program.

Health care services II

Abstract number: OA54
Abstract type: Oral

Characteristics of Referrals of Patients with Non-cancer Diagnoses to a Palliative Care Consultation Service in an Acute Care Hospital

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Aims: The needs of patients with non-cancer (NC) diagnoses who require palliative care support while admitted to an acute care hospital are still unknown. In our urban acute care hospital, NC patients have been accounting for an increasing percentage of referrals for palliative care inpatient consultation over the past five years, from 11% of 489 referrals to 25% of 597 referrals. In order to assess palliative care service needs of NC patients, we evaluated
An Evaluation of the Implementation of the Liverpool Care Pathway in Three Rural Regions of Western Australia

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Aims: The Liverpool Care Pathway (LCP) is a widely recognized clinical guideline for the optimal management of the terminally ill in the last 72 hours of life. Using a quality improvement implementation process, the LCP was introduced in 16 rural/regional hospitals in Western Australia (WA). This study aimed to evaluate whether the systematic use of the LCP improved the quality and cost of end of life care in rural WA.

Methods: Patient, caregiver and health services outcomes were evaluated pre/post implementation of the LCP. Data were captured through medical record audits of the last admission for 415 deceased patients (223 pre/192 post) who were in hospital for more than 24 hours prior to death; a survey of the primary nurse involved in the patient’s care; and a telephone interview with the caregiver (3 months after the patient’s death).

Results: Mean length of stay was 10 days (range 1-121) prior to death. The mean time on the LCP was 5.58 days (range 0-44). Analyses document significant improvements in the appropriate identification of dying patients and documentation of their care pre/post. Communication improved between health professionals and with the patient and their family. Use of the LCP resulted in improved symptom management, improved caregiver satisfaction with care, and a reduction costs through a reduction in inappropriate procedures and investigations.

Conclusion: Use of the LCP in the dying phase is likely to improve end of life care, reduce the use of inappropriate or burdensome life-sustaining interventions and reduce costs once implemented.

Abstract number: OA55
Abstract type: Oral

Differences in Extent and Timing of Referrals to Specialist Palliative Care between Patients with Cancer, Organ Failure and Dementia

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Background: The use of palliative care services (PCS) results in improved outcomes for most people suffering from a life-threatening disease. However, patients potentially benefitting from PCS often fail to access such services and referrals usually occur relatively late. A late referral may not provide enough time to achieve the goals of PCS. To date, little is known about the patterns of referral for patients suffering from different life-threatening conditions. This study aims to describe differences in the extent and timing of referrals to PCS for people dying from cancer, organ failure (OF) and dementia.

Method: Data were achieved through a full-year mortality follow-back study (2010) using the nationwide Sentinel Network of General Practitioners in Belgium. GPs reported weekly all deaths of patients in their practice and registered the care provided in the final 3 months of life.

Abstract number: OA56
Abstract type: Oral
Results: Data of 1151 deaths were studied of which 766 (67%) were non-sudden. Of these 39% died of cancer, 11% of OF and 7% of dementia. Referral to PCS in the last three months of life occurred in 65% of those with cancer versus in 34% and 38% of those with OF or dementia, respectively \((P<.01)\). People older than 85 were significantly less often referred (39%), than people between 65 and 84 (48%) or those younger than 65 (55%). The mean number of days between referral and death for cancer(30), OF(21) and dementia(31) did not differ significantly. With increasing age, however, the number of days between referral and death decreased significantly \((P<.05)\).

Conclusions: The extent of referral to PCS is not equal for all diseases, with particularly people with OF, dementia or people over 85 being underserved. The timing of referral did not seem to differ, but occurs often late for all disease trajectories and mainly for older people. This evidence, at population level, shows a need for effective interventions to increase early referrals to PCS, especially for non-cancer patients and older people.

Abstract type: Oral

Abstract number: OA57

Work Culture among Health Care Personnel in a Palliative Medicine Unit

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Background: Understanding and assessing health care personnel’s work culture in palliative care is important since a conflict between “high tech” and “high touch” is present. Implementing necessary changes in behaviour and procedures may imply a profound challenge due to this conflict. The aim of this study was to explore the work culture at a Palliative Medicine Unit (PMU).

Methods: Health care personnel (N=26) at a PMU in Norway comprising physicians, nurses, physiotherapists and others filled in a questionnaire about their perception of the work culture at the unit. The Systematizing Person-Group Relations (SPGR) method was used for gathering data and for the analyses. This method applies six different dimensions representing different aspects of a work culture (Synergy, Withdrawal, Opposition, Dependence, Control and Nurture) and each dimension has two vectors applied. The method seeks to explore what aspects dominate the particular work culture identifying challenges, limitations and opportunities. The findings were compared with a reference group of 347 ratings of well-functioning Norwegian organizations, named the “Norwegian Norm”.

Results: The health care personnel working at the PMU had significantly higher scores than the “Norwegian Norm” in both vectors in the “Withdrawal” dimension and significantly lower scores in both vectors in the “Synergy”, “Control” and “Dependence” dimensions.

Conclusion: Health care personnel at the PMU have significant different perception of their work culture than “well-functioning organizations” in several dimensions. The low score in the “Synergy” and “Control” dimension indicate lack of engagement and constructive goal-orientation behavior and not being in a position to change their behavior. The conflict between “high tech” and “high touch” at a PMU seems to be an obstacle when implementing new procedures and alternative courses of action.

Abstract number: OA58

Abstract type: Oral

Variations in ‘Out of Hours’ End of Life Care Service Provision across Primary Care Organisations in England and Scotland: The Case of Nursing Care

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Aim: Access to end of life (EoL) out of hours (OoH) care is a key factor in patients being able to remain at home if they wish, and in preventing avoidable hospital admissions. In line with previous research, the English Department of Health End of Life Strategy saw variations in availability of 24/7 nursing services as a particular problem. We explored EoL OoH care variations across Primary Care Organisation
geographical areas (PCOs) in England and Scotland, and providers and commissioners’ views about service provision. We use these data to explore the availability of 24/7 nursing care.

Methods: Semi-structured telephone interviews in 2010/11 with informants knowledgeable about the commissioning and/or provision of EoL or OoH care in PCOs.

Results: 114 PCOs were sampled. 45% participated. Participating PCOs had larger populations than all PCOs.

In emerging findings, half (49%) of PCOs reported that district (community) nursing was available 24/7 across their area. 31% reported that it was available for part of the OoH period, while 12% reported that its provision varied across the PCO.

Other services included emergency rapid response teams (65% PCOs had available), night sitters/respite care (98%), and hospice at home/augmented home care services (66%). Exploratory analysis indicated differences between PCOs with low and high levels of 24/7 district nursing in provision of other nursing services, and in prevalence of co-ordinating services.

Conclusion: Many patients do not have access throughout the OoH period to district nursing. As proposed in the English EoL Strategy, a variety of services including rapid response teams seem to be being commissioned in place of 24/7 district nursing, as well as to supplement it. The acceptability, effectiveness and costs of different approaches to meeting nursing needs OoH warrants investigation.

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Abstract number: OA59
Abstract type: Oral

Age and Region Were Strongly Related to Admittance among Patients Referred to Specialized Palliative Care in Denmark

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Background: Not all patients referred to specialized palliative care (SPC) are actually admitted to SPC. SPC services having a limited capacity must prioritize.

Objective: To investigate - among patients in Denmark referred to SPC - if differences exist in admittance to SPC.

Method: The analyses were based on data from the Danish Palliative Care Database: a national quality of care database for SPC. It is mandatory for all SPC units (N=36) to register all patients referred to SPC. Among all patients referred to SPC in 2010 who died in 2010 we carried out logistic regression analyses of the associations between gender, age, diagnosis and geographic region, respectively, and the likelihood of admittance to SPC (outcome).

Results: Overall, the admittance rate (proportion of patients referred to SPC and fulfilled referral criteria who were admitted) was 78% (4,241/5,469). The analyses showed no difference in admittance in relation to gender. In relation to diagnosis, age and region there were significant differences between groups (all p<0.001). Patients with leukemia and unknown cancer had the lowest probability of admittance. Admittance rate decreased with older age: patients aged 31-40 and 41-50 years had OR=2.2 and OR=2.5 of admittance when compared to the 80+. The Capital Region had the lowest (67.4%) while the Zealand Region had the highest admittance rate (88.2%) with an OR=3.6 compared to the Capital Region. A multivariate logistic regression analysis with all the four covariates showed almost identical results.

Conclusion: Among referred patients fulfilling referral criteria, older patients, those having leukemia and unknown cancer, and those living in particular regions had lower likelihood of admittance to SPC. Thus, there is clear geographical inequality in Denmark. Whether the reduced admittance of older patients and specific diagnoses can be explained by smaller need is unknown.

Pain II

Abstract number: OA60
Abstract type: Oral

Do Corticosteroids Provide Analgesic Effects in Cancer Patients? A Systematic Review

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Background: Corticosteroids are frequently used in cancer patients, also for their analgesic properties. However, the evidence for analgesic effects of corticosteroids in palliative care is not established.

Methods: A systematic literature search was performed. Eligible studies were RCTs comparing corticosteroids with control or placebo in adult patients with cancer pain already on standard pain treatment. Search string for Pub Med, adapted for EMBASE and CENTRAL: steroids/therapeutic use, pain, controlled clinical trial, and neoplasms, including relevant synonyms. The papers were evaluated according to the GRADE system by two independent reviewers.

Results: The search provided 477 references; only three of these were eligible for quality assessment. Another two trials identified by reference lists were also assessed. Four of the five studies were excluded from the efficacy analysis: two for not reporting adequate outcomes for pain; one due to low pain intensity level (PI) at baseline; and one for heterogeneous study groups.

The remaining study was placebo controlled double-blind cross over (methylprednisolone 16 mg twice daily or placebo) with intervention period of 5 days. Twenty eight of 40 included patients were evaluable for pain. PI (VAS 0-100) was lower in steroid group compared to placebo (mean): 36.8 (SD 14) vs 50.1 (SD 15) (p< 0.01). Analgesic consumption was lower in steroid group compared to placebo (capsules with weak opioid and dipyrone) (mean): 1.8 (SD 1.7) vs 3.3 (SD 1.5) (p< 0.05). Among the excluded studies one reported significant effect in improving pain at each weekly evaluation; another study no effect; and finally one reported lower opioid related side effects in steroid group.

Conclusion: Corticosteroids may have a moderate analgesic effect in cancer patients. The paucity of relevant studies was striking; consequently the evidence was graded “very low”. More studies addressing this question are required. Sykehuset Telemark funded the study

Abstract number: OA62
Abstract type: Oral

Biomarkers as Possible Indicators for Pain Experience and Treatment Outcome

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Aim: To evaluate the relative clinical efficacy of the fast-acting fentanyl formulations, intranasal fentanyl spray (INFS), fentanyl pectin nasal spray (FPNS), oral transmucosal fentanyl citrate (OTFC), fentanyl buccal tablet (FBT), fentanyl sublingual tablets (FST), and fentanyl buccal soluble film (FBSF), as well as oral morphine (OM), in the management of breakthrough cancer pain (BTCP).

Methods: A systematic literature review (Medline, Embase, BIOSIS; 1996-2010) identified 10 similarly designed randomised controlled trials (RCTs) investigating the efficacy of INFS, FPNS, OTFC, FBT, FST, FBSF and OM for the treatment of BTCP in adult cancer patients. The endpoint of interest was pain intensity difference (PID, reported on a 0-10 numeric rating scale) up to 60 minutes after intake. Results of all RCTs were analysed using a network meta-analysis.

Results: INFS, FPNS, FBT and OTFC produced greater PIDs than placebo at all time points tested, with INFS providing the greatest reductions over placebo in each case: mean PID (95% credibility interval) for INFS vs placebo of 1.7 (1.4-2.0) at 15 minutes, 2.0 (1.6-2.3) at 30 minutes, 2.0 (1.5-2.4) at 45 minutes, and 1.9 (1.5-2.4) at 60 minutes. FST and FBSF were better than placebo from 30 minutes, and OM from 45 minutes.

In terms of the PID for INFS relative to the other opioids, INFS was the most efficacious treatment at 15 and 30 minutes after intake: mean PID (95% credibility interval) for INFS vs FPNS was 1.1 (0.6-1.6) at 15 minutes and 0.8 (0.2-1.5) at 30 minutes. The greater efficacy of INFS continued until 30 minutes for FPNS and FBT, 45 minutes for OTFC, and 60 minutes for FST, FBSF and OM.

Conclusion: Based on the currently available evidence, it can be concluded that INFS is expected to provide the greatest improvement in the treatment of short-duration episodes of BTCP. As breakthrough pain often has a rapid onset of action, the greater efficacy of INFS over other opioids in the first 30 minutes seems critical.
increase in some signalling molecules. It was demonstrated that the administration of opioids and the consecutive pain relief could influence the level of these biomarkers. Monocyte chemotactic protein-1 (MCP-1), macrophage inflammatory proteins (MIP) 1α and 1β, interleukins (IL) 7 and 18 as well as osteoprotegerin (OPG) have been associated to pain, opioid therapy and inflammation, which seems to play a major role in the development of pain. Therefore, we performed a prospective study in a cancer patient population with tumor related pain analyzing the change of the profiles of these biomarkers under opioid therapy.

**Methods:** The afore mentioned 6 biomarkers were determined in peripheral venous blood of 44 caucasian patients with pain levels higher than 5 of 10 on the numeric rating scale (NRS). Blood was taken before start of pain treatment which consisted of either oral or parenteral morphine hydrochloride in a fixed dose-scheme and after relief of pain > 3 points on the NRS scale. Cytokine levels were determined by use of commercially available ELISAs.

**Results:** Of 44 patient six patients had to be excluded because of missing values. From the remaining 38 patients, 21 were female and 17 male with a median age of 62.5 years (range 43-89). All patients had developed distant metastases and had prior analgesic therapy. Mean NRS score before treatment was 6.33 and after 2.88, respectively. In a nonparametric Wilcoxon test all candidate biomarkers except MIP-1β (p = 0.07) showed a statistical significant change between the two measurement points. P-values for this change were 0.016 for IL-7, 0.008 for IL-18, 0.001 for MCP-1, 0.001 for MIP-1α, and < 0.001 for OPG respectively.

**Conclusions:** We conclude that these investigated biomarkers could be connected to opioid treatment response of cancer-related pain and these findings warrant further evaluation.

Abstract number: OA63
Abstract type: Oral

**Which Domains Should Be Included in a Cancer Pain Classification System? Analyses of Longitudinal Data**

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**Aims:** The overall aim of the present study is to contribute to the development of a new cancer pain classification system.

**Methods:** Data from a multicentre, observational longitudinal study of cancer pain patients were analysed. A cross-sectional analysis of patients on opioids at inclusion (analysis A) and a longitudinal analysis on patients just admitted to palliative care (analysis B) were carried out. Outcome measures were pain on average, worst pain, and pain relief at study entry, and at day 14, respectively. Univariate and multivariate regression models were applied to test the explicative power on pain outcomes of a series of known pain domains, among which incident pain (IP), psychological distress (PD), neuropathic pain (NP), pain localisation, sleep disturbances, total morphine equivalent daily dose (MEDD), use of non-steroidal anti-inflammatory drugs (NSAIDs), addiction, cancer diagnosis, and localisation of metastases.

**Results:** In the two analyses, 1529 (A) and 352 (B) patients were included, respectively. The sample characteristics were: males 53% in A and 61% in B, respectively, mean age 64 / 65, mean Karnofsky performance status 65% / 63%. Mean pain scores were: average pain 4.4 / 5.0, worst pain 6.8 / 7.5, and pain relief 58 / 43. MEDD was 87 / 66 mg. IP was present in 52% / 57%, and 26% / 25% had NP. IP, NP, pain localisation, MEDD, use of NSAIDs, and sleep were associated with one or more of the pain outcomes in analysis A., while initial pain intensity, initial pain relief, IP, localisation of pain, cancer diagnosis, and age were predictors in the longitudinal analysis. Identified domains explained 16 to 24 % of the variability of the pain outcome.

**Conclusion:** Although initial pain intensity emerged as the strongest predictor of pain outcome after two weeks, and incident pain was confirmed to be a relevant domain in cancer pain classification, the models explained only a minor part of the variability of pain outcomes in cancer patients.

Abstract number: OA64
Abstract type: Oral

“We All Talk about it as though We’re Thinking about the Same Thing”: Healthcare Professionals’ Goals in the Management of Pain due to Advanced Cancer - A Qualitative Study
Aims: Cancer pain remains a significant problem worldwide. As well as challenges relating to the assessment and measurement of pain, barriers still exist which impede the successful treatment and there is no consensus as to what constitutes good pain control. Despite the plethora of research tools available to assess pain, little is known about what patients and healthcare professionals (HCPs) feel is important in pain management. This study aimed to explore what goals HCPs hold when managing pain.

Methods: HCPs involved in the management of cancer pain were purposively sampled and interviewed using a semi-structured technique. Data were analysed using the constant comparison technique, based on the principles of grounded theory.

Results: Analysis of the interviews revealed four main themes: assessing pain, managing pain, managing expectations, and building relationships. Managing pain included helping patients to maintain function and sleep, but also involved finding the meaning of the pain, being with, educating and empowering, and maintaining hope and a sense of self for the patients. HCPs used different terms when managing pain, such as ‘pain control’, but found it difficult to define these terms. Managing patients’ expectations was seen as an important goal for HCPs in managing pain but it wasn’t always clear how these expectations had been elicited. The HCPs discussed the importance of building therapeutic relationships but alluded to the tension between being patient-centred and controlling pain, particularly when patients were reluctant to increase opioids.

Conclusion: The interview findings suggest that the use of goal setting, a technique used commonly in the management of chronic pain, would allow explicit joint identification of goals and expectations and a negotiated patient-centred outcome measure. The setting of realistic targets may also protect HCPs from burnout by preventing a sense of failure.

Cancer pain classification

Abstract number: INV24
Abstract type: Invited Speaker

Is There a Need for a Comprehensive Classification System of Cancer Pain?

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Cancer pain affects about 48% of patients with early-stage cancer, and between 64% and 75% of patients with advanced disease. Pain is often of moderate to severe intensity for many patients and undertreatment is common. Deandrea et al. reviewed 26 studies that examined analgesic prescribing for cancer patients and found that nearly half of cancer patients received inadequate analgesia for their pain.

A recently published review summarised the most important barriers to good pain control. Among these was inadequate pain assessment, which included attention to intensity as well as underlying pain aetiology and pain mechanism. One explanation for inadequate analgesic prescription could be a failure to identify important pain mechanisms and other factors that adversely affect the outcome of pain management.

This session will cover the epidemiology of cancer pain and the challenges faced when characterising cancer pain. The lack of standardised and systematic assessment and classification tools for cancer pain has been identified as an important reason for the under treatment of cancer pain. There is now a need for a taxonomy and agreed classification system for cancer pain to promote good clinical practice and to allow research to progress.
A systematic literature review identified six formal classification systems for CP, among these the Edmonton Classification System for Cancer Pain (ECS-CP). No system had been widely applied in clinical practice or research. Results from this review, previous studies, studies on the ECS-CP, two expert surveys, and patient interviews constituted the basis for planning analyses of empirical data.

Study 1: Cross-sectional data from 2294 opioid treated cancer pts. Ten domains were associated with pain intensity (PI) and/or pain relief (PR) (0-10 numerical rating scale, NRS-11): breakthrough pain (BTP), neuropathic pain (NP), localisation of pain, opioid dose, non-opioids, psychological distress (PD), sleep, addiction, cancer diagnosis, and localisation of metastases.

Study 2: Longitudinal data from 1801 pts. with cancer pain. Using PI and PR (NRS-11) at day 14 as outcomes, the domains PI and PR at study entry, BTP, localisation of pain, age, and cancer diagnosis were identified as predictors. PI, BTP, NP, and PD have been regarded as key domains for cancer pain classification. The present results also suggest to consider PR, localisation of pain, analgesic treatment, sleep disturbances, and cancer diagnosis. Further work should focus on choosing the most appropriate and the optimal number of domains for the ICSCP. Next, consensus must be reached on how to assess these domains, and on the appropriate outcomes. One way to implement the future ICSCP into research and clinical practice could be as part of a computer based decision support system.

Abstract number: INV26
Abstract type: Invited Speaker

Validation of a Pain Classification System for Cancer Pain
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There is no universally accepted system to accurately predict complexity of cancer pain management. There is increasing interest and research collaboration toward achieving this goal. The raises the question of how such a system should be developed and validated.

The Edmonton Classification System for Cancer Pain (ECS-CP) was developed from the original Edmonton Staging System (ESS) for Cancer Pain (1989) and the revised ESS (rESS) (2005). This has given us over 20 years of experience in using a variety of validation approaches. The approach has evolved from small local groups using literature reviews and clinical experience to develop the initial ESS. Subsequent validation efforts matured to international construct validation using a modified Delphi approach and multicentre provincial and international predictive validation research publications. The predictive validation work required the use of relevant outcomes. Stable pain control, opioid doses, use of adjuvant approaches and interdisciplinary support were all considered. The lessons learned from our validation experiences to date will be discussed and considered along with possible alternatives as we look to future research efforts toward achieving the holy grail of a common language for classifying and comparing cancer pain across diverse oncology and palliative care settings.

Poster discussion session II

Abstract number: P444
Abstract type: Poster Discussion

Analyzing Phase III Studies in Hospice / Palliative Care. A Solution that Sits between Intention-to-Treat (ITT) and per Protocol Analyses: The Palliative-modified ITT Analysis
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Intention-to-treat (ITT) analyses are the standard way to evaluate randomized controlled trials (RCTs) to minimise Type I errors related to differential rates of non-completion from one study arm. This paper aims to define a better way of balancing Type I and Type II errors in hospice / palliative care RCTs’ analyses.

People in palliative care often die sooner than predicted as a direct result of disease progression some of whom will be participating in RCTs and who will therefore withdraw or die after randomization for reasons unrelated to the intervention. This proportion of withdrawals is statistically negligible in other clinical disciplines, but commonplace in hospice / palliative care settings.

ITT analyses in hospice / palliative care creating a systematic bias away from the true effect. ITT analyses in hospice / palliative care that deem all withdrawals to be treatment failures or that impute data from deteriorating participants systematically underestimate the benefits of interventions, reducing the power of these studies. Equally unacceptable would be a per protocol analysis that excludes all withdrawals after randomization as this will underestimate toxicity. A modified analytic approach is needed on a continuum between ITT and per protocol analyses.

To address data after randomization where there is a high rate of withdrawals due to death or deterioration,
criteria need to include being: pre-specified in the original protocol; clinically absolutely due to disease progression; equally distributed across all study arms; identified by the blinded Independent Data Monitoring Committee (IDMC) as being unrelated to the intervention(s); and accounted for in the study’s CONSORT diagram. Such data should not be included in analysis of the primary outcome.

Arguably, the palliative-modified ITT analysis should be the primary evaluation of hospice / palliative care phase III studies but, as a minimum, should routinely be the key sensitivity analysis.

Abstract number: P445
Abstract type: Poster Discussion

Recruiting Patients with Advanced Malignant and Non-malignant Disease: Lessons from a Palliative Care RCT
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Aims: Recruiting patients to palliative randomised controlled trials (RCTs) is challenging. We will describe differing recruitment trajectories for patients with advanced cancer and non-cancer disease to a palliative RCT, activities undertaken to achieve targets and their impacts, and lessons learned to inform future RCTs.

Methods: Analysis of descriptive recruitment statistics (patient identification, response and completion rates) to Phase II pilot (COPD only) and Phase III pragmatic single-blind fast track RCT of a breathlessness intervention service for advanced disease; Phase III included sub-protocols for cancer and non-cancer diseases. Documentary analysis of: Recruitment Activity Log, Trial Management and Advisory Group minutes and fieldnotes.

Results: Recruitment targets for patients with non-cancer disease were achieved. The route to recruitment was service-referral thus referral rates impacted on recruitment alongside response rates. Cancer patient recruitment was far slower despite concerted efforts to increase referrals by raising the service profile. Cancer referrals only improved when researchers attended clinics, supporting clinical staff in patient identification: recruitment more than tripled from 0.8 to 3.0 patients/month. Three possible reasons for this:

1) dedicated time,
2) reciprocity and
3) established relationships.

Predictably, response rates remained lower for patients with cancer than for those with non-cancer disease.

Conclusions: Recruitment was partly referral-driven, thus gate-keeping did not explain differences. Clinical interprofessional relationships consolidated in Phases 0-II drove early non-cancer referrals. Local palliative care services pre-existed for patients with cancer. Consideration of the natural history and context of a service is thus important in predicting recruitment. Pilot trials should include qualitative elements and all disease groups. Placing researchers in relevant clinical settings is helpful.

Abstract number: P427
Abstract type: Poster Discussion

How Many People Need Palliative Care? A Refined Method to Estimate the Size of a Palliative Care Population Nationally
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Context: Understanding the need for palliative care is essential in planning service provision.

Aim: To estimate numbers needing palliative care in England, including those with malignant and non-malignant conditions.

Methods: Using secondary data analysis, we refined the approach of Rosenwax et al1, who derived minimum, mid-range and maximum estimates of population need. This was applied to a cohort of people who died in England between 1 Jan 2006 and 31 Dec 2008 using the Linked Hospital Episode Statistics/Office for National Statistics Mortality file, supplied by the National Health Service Information Centre.

Results:
1) Our minimum estimate adopts a more detailed and accurate breakdown of ICD 10 codes (compared to Rosenwax et al1) to encompass eight disease categories.
2) Our lower mid-range estimate extends the low estimate by including cases admitted to hospital with the same conditions in the year before death, in addition to deaths for which Alzheimer’s, dementia, senility or chronic renal failure is recorded as a contributory cause.
3) Our upper mid-range estimate includes all deaths with any mention of any of the disease categories used for the minimum estimate as underlying or contributory cause of death in the death certificate.
4) Our maximum estimate includes all deaths except those during pregnancy and childbirth, puerperal deaths and from external causes.
Using these categories, we estimate an annual minimum of 63% of all deaths in England (297,985 per annum) may benefit from palliative care. The lower and upper mid-range estimates project between 326,685 and 387,067 deaths per annum (69 and 82% of all deaths). The maximum population estimate projects 456,767 deaths per annum (97%).

Conclusions: We have refined a method to provide population estimates of palliative care need at national level. This provides valuable means of estimating and planning for future palliative care need.


Abstract number: P263
Abstract type: Poster Discussion

An Examination of Weight Loss and Body Image Concerns for Advanced Cancer Patients and their Caregivers
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Background: Cancer and its treatments can significantly alter patient’s body image, particularly during advanced stages of illness. Our aim was to examine associations between body mass index (BMI), weight loss, and body image for advanced cancer patients and their caregivers.

Methods: Patients with different levels of BMI and their caregivers were recruited from the Supportive Care Clinic. Body image was assessed using the Body Image Scale (BIS) and 4 questions of the Multidimensional Body-Self Relations Questionnaire (MBSQR). Symptom burden was assessed using the Edmonton Symptom Assessment System (ESAS) and the Hospital Anxiety Depression Scale (HADS). We also assessed patient’s sexuality using the EORTC H&N 35. Caregivers were asked to assess patients’ body image satisfaction using the BIS. We also asked them to rate their quality of life using the Caregiver Quality of Life Index-Cancer (CQOLC) and to rate their overall distress and their distress regarding patient’s weight using the distress thermometer (DT).

Results: 81 patients and 30 caregivers were included in this study. 48 (59%) patients had experienced weight loss of ≥10% of their usual weight during the previous 6 months. The mean BIS score for the entire sample was 11.23 (SD, 7.24). BIS score was significant correlated with weight loss (r=0.26; p=0.020), anxiety (HADS-A, r=0.54; p< 0.001; ESAS anxiety, r=0.356 ;p=0.001) , depression (HADS-D, r=049; p< 0.001; ESAS depression, r=0.41 ;p<0.001), sexual interest (r=0.30; p=0.009), fatigue (r=0.32; p= 0.005), and feeling of well-being (r= 0.31; p< 0.001). We found significant correlation between caregiver BIS score, caregiver’s own quality of life (CQOLC; r=0.48; p=0.007), and caregiver’s distress regarding weight (DT; r=0.54; p=0.002).

Conclusion: We found that weight loss was associated with severe body image concerns; this body image concerns were strongly associated with psychosocial distress.

Abstract number: P364
Abstract type: Poster Discussion

Euthanasia and Physician-assisted Suicide in Elderly Patients without a Terminal Disease: The Dutch Public Opinion. Results from the KOPPEL Study
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Introduction: The Dutch Euthanasia Act regulates euthanasia and physician-assisted suicide (PAS) in case of unbearable and hopeless suffering on the explicit request of a patient. A current topic of debate is whether elderly patients who are “weary of life” but do not have a terminal disease should be enabled to receive euthanasia or PAS. We investigated the opinions of the Dutch general public about this matter.

Methods: In 2010, a cross-sectional survey was conducted among a representative panel of the Dutch population, age 18-95 (n=1960, response rate 78%), using an online questionnaire. Opinions about the circumstances in which euthanasia and PAS should be acceptable were assessed using statements and vignettes. Several statements were also assessed in survey in 2002.

Results: In 2010, 65% agreed with the vignette in which a physician performs euthanasia in terminally ill cancer patient. Euthanasia in case of an elderly person who is weary of life, without having a terminal disease was approved by 26% of the respondents. Furthermore, 21% agreed with the statement “Euthanasia for elderly patients without a serious medical condition is in my view acceptable”. Of the respondents, 36% in 2010 and 45% in 2002 were in favour of a “suicide pill” for the oldest old that enables them, if they want so, to end their life (p< 0.001). These persons were more likely to be higher educated (OR 1.7, CI:1.3-2.1) and not religious (OR 1.9 CI:1.5-2.3). Age (>55) however, was unrelated (OR 1.2, CI:0.9-1.5).

Conclusion: While a large majority of the Dutch public considered euthanasia and PAS acceptable for patients whose suffering is rooted in a terminal disease, there is much less societal support for euthanasia and PAS for elderly patients who are weary of life without a terminal disease, which seems to diminish compared to 8 years ago.
**Legal and Regulatory Barriers in Accessing Opioid Medicines: A Pilot Study in Six European Countries Using a ‘Quick Scan’ Method**

**Aims:** Identify legal and regulatory barriers that may impede access to opioid medicines in six European countries.

**Methods:** A method to identify legal and regulatory barriers to opioid medication was developed focusing on six different categories of barriers (importation/exportation, prescribing, dispensing, manufacture, registration and miscellaneous). As a pilot study in six selected European countries (Bulgaria, Cyprus, Greece, Serbia, Slovenia and Turkey), legislation was obtained from key experts who were selected based on their expertise in the field of pharmaceutical law and health policy. The legislation was analyzed (‘quick scanned’) using WHO criteria. Overly restrictive provisions were identified, as well as provisions that contain stigmatizing language and incorrect use of definitions. The selected provisions were independently scored by two reviewers into two categories: 1) a probable barrier and 2) a potential barrier. A barrier was recorded if both reviewers concurred with each other.

**Results:** In total (sections of) 35 documents were obtained and (partly) analyzed for the selected countries. All six countries showed legal and regulatory barriers in the areas of prescribing (most frequently observed barrier) and dispensing. Several (but not all) countries showed barriers in other categories, but no barriers concerning the manufacture of opioid medicines were identified. Five countries showed stigmatizing language and incorrect use of definitions in their legislation.

**Conclusion and discussion:** This pilot study shows that legal and regulatory barriers can be identified using a quick scan method. Commonalities in the selected countries include the areas of prescribing and dispensing as main barriers and the use of stigmatizing language and incorrect use of definitions. Additional research is needed to assess the extent of the barriers and their impact on access to opioid medicines.

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**Identification of Training Needs for Children’s Palliative Care**

**Aims:** Few studies have been undertaken to assess training needs for children’s palliative care (CPC). Thus a survey was undertaken to understand training needs for CPC in order to develop appropriate training programs.

**Method:** An online survey was developed and was live for 4 months from April 2011 & invitations sent to members of key CPC organisations such as ICPCN, ACT etc.

**Results:** Of the 248 respondents from 54 countries, 33% were doctors, 46% nurses and 21% other professions such as clinical officers, OTs, physios, religious leaders, social workers & teachers. On a scale of 1-5, Doctors were most knowledgeable in pain assessment & management ($\bar{x}$=4.15), the basics of CPC ($\bar{x}$=4.15) & cancer ($\bar{x}$=4.11). Nurses were most knowledgeable in working with families ($\bar{x}$=4.02) & self care ($\bar{x}$=3.9). Other professions were most knowledgeable in working with families ($\bar{x}$=4.2) & communities ($\bar{x}$=4.18). They all felt most confident in communication (Drs $\bar{x}$=3.92, Nurses $\bar{x}$=3.88, Others $\bar{x}$=4.27) & working with families (Drs & Nurses $\bar{x}$=3.92, Others $\bar{x}$=4.18) with doctors also feeling confident in pain assessment & management ($\bar{x}$=3.92). Doctors were least knowledgeable about HIV/AIDS ($\bar{x}$=2.81), dermatology ($\bar{x}$=3.18) & development of CPC services ($\bar{x}$=3.19), & nurses about HIV/AIDS ($\bar{x}$=2.91) & Ethics & the Law ($\bar{x}$=3.02). Other professions were least knowledgeable about dermatological ($\bar{x}$=2.51) & urinary ($\bar{x}$=2.67) issues. Both doctors & nurses felt least confident about caring for people with HIV/AIDS ($\bar{x}$=2.7, $\bar{x}$=2.9). Nurses also had low confidence in counselling ($\bar{x}$=2.98) & doctors in spiritual care ($\bar{x}$=2.83). Other professions had low confidence in dermatological ($\bar{x}$=2.62) & neurological ($\bar{x}$=2.69) issues.

**Conclusion:** Further analysis is ongoing to assess how training needs differ according to regions in which respondents live, however understanding training needs will help shape the development of an international training strategy for CPC.

Funded by OSI.
Abstract number: P270
Abstract type: Poster Discussion

Experiences and Characteristics of Episodic Breathlessness (EB) in Patients with Advanced Disease - A Systematic Review

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Background: Episodic breathlessness (EB) is an increase in breathlessness occurring intermittently in patients with or without underlying continuous breathlessness. Although reported to be a highly prevalent in advanced disease our understanding of this distressing symptom is still limited.

Aim: To identify, critically appraise, and synthesize the evidence on EB in advanced disease regarding definition, characteristics and patients’ experiences.

Methods: Systematic review using the databases MEDLINE, EMBASE, CINAHL, PsycINFO, British Nursing Index, Cochrane Library (from 1950 until March 2011), hand search and personal contacts to authors in the field. Search terms included the combination of ‘episodic’ and ‘dyspnoea’ (and synonyms) with five different diseases (COPD, lung cancer, CHF, MND, ILD). Selection criteria: patients with advanced disease and specific information about EB based on original research. All retrieved studies were assessed by two independent reviewers.

Results: 7,584 references were identified and 27 studies were included in this review. Only eight studies explored EB as a primary outcome and only five studies provided a definition. EB is characterized by high prevalence (81-85%), high frequency (daily), short duration (often less than 10 min) and severe peak intensity, but these data are only based on a few studies in lung cancer, CHF and COPD. EB is perceived as a frightening symptom with multidimensional impact on patients’ quality of life. EB either develops without any known trigger or is triggered by physical exertion, emotions or environmental influences, and some patients are aware of a prodromal phase to EB.

Conclusion: EB is a common and burdensome symptom in patients with advanced disease, but information about characteristics and treatment options is limited. As there is no common terminology, an agreed definition is needed to foster research in order to develop effective treatments for EB.

Founding source: BMBF grant 16KT095

Research methodology II

Abstract number: OA65
Abstract type: Oral

The EAPC Basic Dataset. Results from an International Delphi Process

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Background and aim: One of the barriers identified in palliative care research is the lack of common criteria to describe the population. This Delphi process was conducted to obtain consensus on a basic set of core variables to describe or classify a palliative care population.

Methods: 103 experienced palliative care clinicians and researchers from 35 countries and editors of 14 palliative care journals were invited to participate. Based on a literature review and analyses of existing national minimum datasets, a list of 18 proposed variables was presented in the first Delphi round. The two first rounds focused on which variables to include. Several new variables were proposed. The three last Delphi rounds focused on how the agreed variables should be recorded and/or measured. The Delphi exercise was conducted using the web-based system SelectSurvey.NET. Consensus was defined as at least 70% agreement.

Results: 65 experts from 30 countries participated. The five Delphi rounds were conducted between 02 Feb and 11 Aug 2011. High consensus was reached on 30 variables, divided between a patient form and a health care personnel form. Patient form variables: Date of birth, gender, living situation, education, ethnicity, and 12 symptoms; anxiety, lack of appetite, depression, drowsiness, nausea, pain, shortness of breath, tiredness, wellbeing, insomnia, constipation, and vomiting. Health care personnel form: Date of birth, principal diagnosis, date of the principal diagnosis, stage of the cancer disease, site of metastases, present anti-cancer treatment, main additional diagnoses, medication, weight loss, performance status, cognitive impairment, place of care, and provision of care. It was more difficult to agree upon how to record the variables, but consensus was reached on all except ethnicity, vomiting, and weight loss.
Conclusion: Consensus was reached on a set of core variables and how they should be recorded. A multi-centre study is underway to pilot the dataset.

Abstract number: OA66  
Abstract type: Oral  
What’s in a Name? A Systematic Review of Concepts and Definitions for “Supportive Care”, “Best Supportive Care”, “Palliative Care” and “Hospice Care”  
Hui D. 1, Mori M. 2, Parsons H.A. 1, De La Cruz M. 1, Torres I. 1, Kim S.H. 3, Dev R. 1, Hutchins R. 1, Liem C. 1, Bruera E. 1  
1MD Anderson Cancer Center, Houston, TX, United States, 2Seirei Hamamatsu General Hospital, Shizuoka, Japan, 3Myong Ji Hospital, Kwandong University, Gyeonggi, Korea, Democratic People’s Republic of  
Aims: We previously found that commonly used terms such as “supportive care”, “best supportive care”, “palliative care” and “hospice care” were rarely and inconsistently defined in a sample of palliative oncology studies. We conducted a systematic review to further identify concepts and definitions for these terms.  
Methods: Our librarian searched MEDLINE, PsycInfo, EMBASE and CINAHL for published articles between 1948 and 2011 aimed to conceptualize, define or understand these terms. Two researchers independently reviewed each citation for inclusion, and then extracted the concepts/definitions when available.  
Results: 9/32, 25/182 and 12/42 articles from our search focused on conceptualizing “(best) supportive care”, “palliative care”, and “hospice care”, respectively. For “best/supportive care”, 5/9 articles discussed its misuse in randomized controlled trials and 4/9 focused on clarifying it. We found 13 definitions for “best/supportive care”, ranging widely from symptom management during cancer therapy to survivorship care. For “palliative care”, we identified 24 unique definitions. Definitions cited included those from 8 organizations, 2 consensus workgroups and 2 textbooks, with the World Health Organization definition cited most often (N=14/25). Fundamental concepts defining “palliative care” included quality of life/symptom control (23/25), interdisciplinary care (14/25), caregiver care (22/25) and advanced illness (24/25). 12/25 studies discussed palliative care earlier in the disease trajectory. For “hospice care”, 17 different definitions were identified in 12 studies. The key concepts included symptom control (12/12), interprofessionalism (9/12), caregiver care (10/12) and bereavement (8/12).  
Conclusion: We identified defining concepts for “best/supportive care”, “palliative care” and “hospice care”, and developed a preliminary conceptual framework unifying these terms along the continuum of care to help build consensus toward standardized definitions.

Abstract number: OA67  
Abstract type: Oral  
Planning the First English End of Life Care Survey  
Hunt K.J., Addington-Hall J.  
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Aim: The 2008 English End of Life Care (EOLC) Strategy recognised the importance of evaluating EOLC experiences, and recommended an annual EOLC survey to measure the Strategy’s impact and to provide comparative data to local commissioners and providers. The VOICES questionnaire, completed by bereaved relatives, was recommended for use. The Department of Health commissioned this pilot study to test methods for the national survey.  
Methods: VOICES’ content was refined to match the EOLC pathway, following discussion with user representatives, palliative care staff, and analysis of existing VOICES datasets (VOICES-SF). The Office for National Statistics identified 1422 deaths registered in 2 health districts using stratified sampling. Coroner-registered deaths were excluded. Deaths were randomly assigned to one of 2 trial groups to determine recruitment approach (opt-in vs opt-out). Online completion was available. Organisations for minority ethnic groups collaborated in publicising the survey, interpreting services were provided and advertising posters were translated into 5 languages. Bereavement support structures were initiated.  
Results: Response rate was 33%, and was higher in the ‘opt out’ group (40%, 26%, p<.001). There were no complaints and only 2 informants called the bereavement support line. 19.6% completed online. Minority group response was low. Non-response bias necessitated data weighting. Excluded coroner-registered deaths were significantly different to included deaths on a series of parameters. Statistically significant differences were detected between disease groups and health districts.  
Conclusion: Based on these results, VOICES-SF was used in the first English EOLC survey in 2011. The methods, sample size and analysis of the national survey were determined by pilot findings. Coroner-registered deaths were included for the first time. The national survey’s findings will help ensure patient and carer experiences are at the centre of EOLC in England.

Abstract number: OA68  
Abstract type: Oral  
WHO: The Need for Targeted Research on the Pharmacological Treatment of Persistent Pain in Children with Medical Illness  
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What’s in a Name? A Systematic Review of Concepts and Definitions for “Supportive Care”, “Best Supportive Care”, “Palliative Care” and “Hospice Care”  
Hui D. 1, Mori M. 2, Parsons H.A. 1, De La Cruz M. 1, Torres I. 1, Kim S.H. 3, Dev R. 1, Hutchins R. 1, Liem C. 1, Bruera E. 1  
1MD Anderson Cancer Center, Houston, TX, United States, 2Seirei Hamamatsu General Hospital, Shizuoka, Japan, 3Myong Ji Hospital, Kwandong University, Gyeonggi, Korea, Democratic People’s Republic of
University Hospital, Regional Centre of Excellence in Palliative Care, Bergen, Norway, 3Haukeland University Hospital, Multidisciplinary Pain Clinic, Bergen, Norway

**Aims:** The WHO has recently undertaken an update of the 1998 WHO Cancer Pain Relief and Palliative Care in Children guidelines. The new guidelines are intended to cover a wider paediatric pain patient population and are entitled *WHO Guidelines for the Pharmacological Treatment of Persistent Pain in Children with Medical Illness.*

**Methods:** The new guidelines were developed using the GRADE approach for evidence synthesis and grading of recommendations.

**Results:** This rigorous process led to the identification of several research gaps and the formulation of a research agenda for tackling the priority areas which deserve urgent attention by the international scientific community. Clinical studies are needed on paracetamol, NSAIDs, and opioid analgesics. In addition, clinical studies are needed on adjuvant medicines for neuropathic pain. Pharmacokinetic data is lacking and the safety and dosing of non-opioid and opioid analgesics in different age groups needs to be investigated. Further research is needed on chronic pain assessment tools in specific subgroups of patients such as neonates, infants, pre-verbal children and children with developmental problems.

**Conclusions:** As a result of this identified lack of high quality evidence, the WHO has made specific recommendations for a research agenda in this patient population. Given the paucity of clinical research the WHO is now calling for an international collaborative research initiative.

**Funding:** Generous support was received for the development of the guidelines from the Foundation Open Society Institute (Zug), New York, USA; the International Association for the Study of Pain (IASP), Seattle, USA; Ministry of Health, Welfare and Sport, The Hague, the Netherlands; the Mayday Fund, New York, USA; the Rockefeller Foundation, New York, USA; The True Colours Trust, London, United Kingdom, and the US Cancer Pain Relief Committee, Madison, USA.

Abstract number: OA69
Abstract type: Oral

**Methodological Challenges and Opportunities when Undertaking a Cluster Randomised Control Trial in Nursing Homes**

_Kinley J., Hockley J._

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**Background:** In 2008 an English regional training centre to facilitate the implementation of the GSFCH (Gold Standard Framework in Care Homes) programme was commissioned. A hospice based project team to support nursing homes (NHs) was established to implement this programme. A cluster randomised controlled trial (CRCT) was undertaken to evaluate two models of high facilitation alongside an observation arm depicting the usual GSFCH facilitation model. However, undertaking a CRCT outside a university base presented methodological challenges requiring solutions as well as offering opportunities.

**Aims:** To present the challenges and opportunities that arose from undertaking a CRCT from a practice base.

**Methods:** Thirty-eight NHs were recruited across SE England to participate in a two year study. Across all homes data was sought from: deceased residents’ records (n=2447); bereaved relatives (ongoing); and all staff groups (pre-intervention n=2407 and post-intervention n=2418).

**Results:** All but one NH participated throughout the study resulting in a near complete data set. Challenges included: consenting and retaining 38 NCHs; monthly data collection; data input; data analysis. Solutions included: gaining support of NH manager; building a relationship with a specific member of the NH; regular contact with each NHs; flexibility and keeping agreements; the innovative use of 12 volunteers; and, establishing a link with a university site. Opportunities included: data collection over two years ensured: minimal missing data; time to build a relationship with each NH; and ability to provide the participating NHs with data for audit purposes.

**Conclusion:** Undertaking the CRCT from a practice base rather than a university aided recruitment and retention of NHs. However a university link was required to support randomisation and data analysis. This method of joint working may offer a solution to some of the methodological challenges experienced when undertaking practice-based research.

Abstract number: OA70
Abstract type: Oral

**Cancer Symptom Clusters and Statistical Methods**

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**Introduction:** Identification of symptom clusters (SC) vary between studies. We aimed to explore whether SC varied by mathematical technique employed.

**Methods:** We reanalyzed a symptom dataset of 1000 patients with advanced cancer. 38 symptoms were analyzed for severity from a 4 point categorical scale (none, mild, moderate, severe) in 527 patients. Spearman test measured the similarity between 2 symptoms. Hierarchical cluster analysis (HCA) identified SC at various correlation coefficients. Identification of final clusters was based on visual interpretation of the constructed dendograms. Final SC were validated by the K-means cluster method. This technique required only the number of SC to be determined before analysis; no dendograms or cut-off points were needed.

**Results:** N=1000; 55% males; median age 65 years (range 56-72); 62% ECOG PS3 or PS4. The most frequent cancers were lung (24%), gastrointestinal (11%), and breast (9%). HCA identified 16 SC from 38 symptoms using a correlation coefficient of 0.6; 13 SC (0.5); 11 SC (0.4). Regardless of cut-off point used there were always single symptoms that did not cluster with any other symptoms. Five SC were observed regardless of correlation coefficient: 1. Weight loss, anorexia, early satiety, taste changes, dry mouth, lack of energy, fatigue, and weakness 2. Bloating, belching, dyspepsia, hiccough 3. Nausea, vomiting 4. Cough, dyspnea, dysphagia, hoarseness, wheezing 5. Memory problems, hallucinations, confusion.

**Conclusions:** SC derived from severity data were consistent across statistical methodologies. Five SC were consistent irrespective of the clustering method. This data suggest that SC are an important and real clinical phenomenon independent of statistical method used.

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**End-of-life care II**

**Abstract number:** OA71
**Abstract type:** Oral

Caregivers’ Experiences of Managing Medications of Palliative Care Patients at the End of Life - A Qualitative Study

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**Background:** Prescribing in palliative care should aim to minimise polypharmacy and maximise symptom control. Often patients are taking multiple medications at the end of life, many of which are prescribed to manage co-morbidities and do not contribute directly to symptom control. This imposes an unnecessary burden on patients who are already struggling with oral intake. A literature review revealed that, while there are a number of qualitative studies published looking at the experience of caregivers looking after patients at the end of life, there is a dearth of published studies specifically examining the impact of managing medication on caregivers.

**Aims:** The aim of this study was to capture the experience of caregivers managing medications for patients with life-limiting illnesses at home at the end of life. We sought to explore issues regarding the number of medications patients may be expected to take as well as how bereaved caregivers view the responsibility of assisting with medication management. We were interested in caregivers’ views regarding the responsibility of administering “as required” medications to aid with symptom control.

**Methods:** Bereaved caregivers of patients that had died at home under the regional Palliative Care service were contacted by post, approximately six months following the bereavement. They were asked to complete a questionnaire with both closed and open ended questions and were also invited to take part in a focus group. Three focus groups were performed, with a total of 16 participants. The transcripts were analysed using content thematic analysis, as described by Burnard in 1991.

**Results:** Themes that emerged from the focus groups include: the significant burden of polypharmacy on patients at the end of life, the positive impact of subcutaneous infusions and the value of being able to give medications as needed for symptom control. A number of strategies were suggested that might ease the burden of medications at the end of life.

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**Comparing Continuous Sedation until Death and Euthanasia: Professional Caregivers’ Attitudes and Experiences. A Focus Group Study in Flanders, Belgium**

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**Context:** Guidelines about continuous sedation until death sharply distinguish this practice from euthanasia, which is legalized in Belgium.
**Objectives:** To explore professional caregivers’ perceptions of the similarities and differences of continuous sedation until death and euthanasia.

**Methods:** Qualitative data were gathered through four focus groups: two with physicians (n=4 & n=4) and two with nurses (n=4 & n=9). Participants could participate if they were ever involved in the use of continuous sedation until death. Questions pertained to participants’ attitudes of and experiences with the use of continuous sedation. The focus groups took two hours and were recorded and transcribed verbatim. Analyses were conducted by a multidisciplinary research team using constant comparison analyses.

**Results:** Although the differences and similarities between continuous sedation and euthanasia were not specifically addressed in the questions in the focus groups, they concerned a main theme in the accounts of the participants. In reflecting about their practices and views, many participants elaborated on the differences between continuous sedation and euthanasia, particularly as regard to patients’ preferences and requests, decision-making, indications and physicians’ intention. However, some participants stated that the distinction between the two sometimes becomes blurred, especially when the sedating medication is increased disproportionately or when sedation is used for patients with a longer life expectancy.

**Conclusion:** The differences and similarities between continuous sedation until death and euthanasia is an issue for several Flemish physicians in their care for unbearably suffering terminally ill patients. Although guidelines strictly distinguish both practices, this may not always be the case in Flemish clinical practice.

**Abstract number:** OA73

**Abstract type:** Oral

**A Study of Cancer Therapy during End-of-Life Care at a Regional Cancer Centre**

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**Background:** More cancer patients (pts) receive more therapy than before and there is a risk that many are overtreated. Aims of the study were to assess time from end of cancer therapy until death; how many were seen at a palliative care unit (PCU); and whether there were differences depending on age, type of cancer or year of death.

**Methods:** Data were retrospectively collected from medical records at a regional cancer centre on all who died from cancer in 2005 & 2009. Pts characteristics at diagnosis and start of last cancer therapy; number of regimens; whether they were seen at a PCU; time of start & end of last cancer therapy were registered.

**Results:** 616 pts died in 2005; 599 in 2009. 151 pts were excluded (no information of cancer in medical records). Median age was 75; 49% females; 24% had no cancer therapy; median overall survival from diagnosis: 11.1 mos. Last therapy was radiation: 22%; chemotherapy: 27%; surgery: 14%; hormonal: 10 %. 44 pts (4%) died of treatment complications. Median time from end of cancer therapy until death was 2.0 mos. The % who were treated last 14 days (2005: 27%, 2009: 17%; p=.001) and 30 days (2005: 37%, 2009: 29%; p=.011) were lower in 2009 than in 2005 and varied between types of cancer (Table 1). Of the 44% who were referred to the PCU, fewer received cancer therapy last 14 days (PCU: 16%, no PCU: 27%; p<.001) and last 30 days (PCU: 26%, no PCU: 40%; p<.001) but had similar survival (PCU: 13.2 mos, no PCU: 8.5 mos; p=.27).

**Conclusion:** Many pts received cancer therapy the last month of life, the percentage vary between cancer types and was lower in 2009 than in 2005. Pts on the PCU program received less aggressive therapy, but had similar survival. Characteristics of pts at start of last cancer therapy, number of regimens and hospitalizations last month of life will be presented.

<table>
<thead>
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<th>Cancer type</th>
<th>Lung (n=105/113)</th>
<th>Colon (n=85/69)</th>
<th>Breast (n=36/36)</th>
<th>Prostate (n=47/50)</th>
<th>Pancreas (n=32/45)</th>
<th>Other (n=229/218)</th>
<th>All patients (n=534/531)</th>
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<tr>
<td>Cancer therapy within 14 days of death</td>
<td>24% / 12%</td>
<td>7% / 10%</td>
<td>68% / 30%</td>
<td>84% / 63%</td>
<td>18% / 0%</td>
<td>12% / 8%</td>
<td>27% / 17%</td>
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<tr>
<td>Cancer therapy within 30 days of death</td>
<td>39% / 31%</td>
<td>17% / 20%</td>
<td>74% / 42%</td>
<td>84% / 70%</td>
<td>36% / 25%</td>
<td>25% / 16%</td>
<td>37% / 29%</td>
</tr>
</tbody>
</table>

Table 1
The Development of a Generic Dignity Model of Illness Based on Qualitative Interviews with Patients

Van Gennip L.E., Pasman H.R.W., Oosterveld-Vlug M.G., Willems D.L., Onwuteaka-Philipsen B.D.

Context: Since loss of personal dignity in patients is associated with psychological suffering and loss of the will to live, preservation of dignity in the severely ill has become a primary concern in palliative care. To promote dignity conserving care, understanding of what exactly constitutes patients' dignity is necessary.

Objectives: To develop a comprehensive dignity model of illness based on how patients with different illnesses, and in different phases of illness understand dignity.

Methods: Qualitative in-depth interviews were conducted with 34 patients with either different types of cancer, early-stage dementia, or severe chronic illnesses. Data were analyzed with support of Atlas/ti, using latent content analysis and constant comparisons techniques.

Results: We developed a two-step generic dignity model of illness. According to this model, illness symptoms do not affect patients' dignity directly but indirectly by affecting the way patients perceive themselves. We identified three components shaping self-perception:

1) the individual self: the subjective experiences and internally held qualities of the patient;
2) the relational self: the self within reciprocal interaction with significant others; and,
3) the self as object: the self as a social object in the eyes of others.

Illness symptoms may negatively influence one or more of these components, resulting in a possible decline of dignity. Adequate personal coping, access to a supportive network, and good professional care can protect against these detrimental influences.

Conclusions: The merits of the model are two-sided. First, it offers a theoretical framework for further research into patients' dignity. Second, the model can facilitate palliative care by making insightful at the level of individual patients where possible problems pertaining to dignity may be located, and thus were possible intervention can be target at.

Main source of funding: Pieter van Foreeststichting, NVVE, NPV.

What Predicts Realisation of Preferred Place of Death in England? Results from a Post-bereavement Survey

Hunt K.J., Addington-Hall J.

Aims: The End of life Care Strategy for England aimed to improve the quality of end of life care and enable more people to die in their preferred place. Despite the majority
expressing a preference to remain at home at the end of life, hospital remains the most common place of death, particularly for non-cancer patients.

We aimed to explore end of life care preferences and determine predictors of achieving preferred place of death, home death and hospital death.

**Methods:** The Office for National Statistics drew a stratified sample of deaths registered in two health districts between October 2009 and April 2010. The VOICES questionnaire was sent to each informant (n=1422, usually bereaved relative) 6 to 12 months after the death. As planned, data were weighted to account for response bias. Bivariate analyses were conducted using odds ratios and chi squared. Logistic regression was conducted to explore predictors of achieving preferences.

**Results:** 473 returned questionnaires (33%). 35% of respondents reported that the deceased had said where they wanted to die (mainly home 68%). This was apparently documented for 36% of these. Only 1% were reported to have changed their mind about where they wanted to die. Cancer patients were significantly more likely to die at home than those who died from any other condition (p< .001) and significantly more likely to have a record of preferences (OR=5.86). Having a record of preferences was significantly associated with both achieving preference (OR=21.0) and home death (OR=15.9) when adjusting for demographic and service use variables. Conversely, hospital death was associated with a reduction in the odds of having recorded preferences (OR=0.20).

**Conclusion:** Having a record of preferences was the only independent predictor of achieving preferred place of death. This appears to support the current UK emphasis on identifying and recording patient preferences for place of care at the end of life.

**End-of-life care III**

**Abstract number:** OA77  
**Abstract type:** Oral

**Spiritual End-of-Life Care in Dutch Nursing Homes: An Ethnographic Study**

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**Context:** Little is known about spiritual care giving for nursing home residents at the end of life.

**Objectives:** To explore if and how spiritual end-of-life care is provided in Dutch nursing home care, and if and how professional and family caregivers collaborate and communicate on the residents’ spiritual needs.

**Method:** An ethnographic study was conducted in a Dutch nursing home on a psycho-geriatric ward and a ward for residents with physical disabilities between April 2010 and May 2011. Data were collected by two researchers and analysed by a constant comparative approach.

**Results:** Spiritual care giving was not part of the formal care process. Physicians did not actively address spiritual issues, nor did care staff as part of their official job. We identified different ‘levels of communication’: informal communication of the nurses among themselves and formal communication between nurses and physicians. Spiritual issues were only addressed at the informal level and not translated to the formal level. When the resident is likely to die soon the nurses started an informal care process including coddling, the use of music and all kinds of rituals. Major events at the end of life appeared to have psycho-social as well as spiritual aspects. Nurses did not always restrict their involvement to the context of their professional role. Spiritual themes were only informally discussed, after the resident had deceased, by their loved ones and nurses. No significant differences in provided end-of-life care was found between the psycho-geriatric ward and the ward for residents with physical disabilities.

**Discussion:** Spiritual issues were only addressed at the informal level and were not translated to the formal level. Major end-of-life events had distinct spiritual and psycho-social aspects. Our results raise questions about the contribution of spiritual end-of-life care lacking communication between disciplines to spiritual wellbeing and the importance of the informal care process.
a hand-written directive and an official-looking document. The third vignette compared the effect of a family member or a doctor in the role of a designated proxy. The outcome variable was the decision to forego a medical intervention.

**Results:** Compared to the control condition, the odds of avoiding a medical intervention was increased by the advance directive (odds ratio 7.3, 95% CI 4.6-11.5), the proxy (OR 7.9, 95% CI 5.0-12.4), and the combination of the two (OR 35.7, 95% CI 17.9-71.2). The effect of the hand-written directive (OR 13.3, 95%CI 8.8-19.9) was identical to that of the official-looking directive (OR 13.8, 95%CI 9.3-20.6). The effect of the proxy opinion was slightly weaker for the family member (OR 7.8, 95%CI 4.5-13.4) than for the doctor (11.3, 95%CI 6.7-19.0).

**Conclusions:** Advance directives and proxy opinions are equally effective in influencing doctors’ decisions, but having both has the strongest effect. The formalization of the advance directive does not matter, but a doctor is slightly more influential than a family member in the role of a proxy.

**Abstract number:** OA79
**Abstract type:** Oral

**Dementia: What Care Do Patients and Carers Need in the Last Year of Life and Time Surrounding Death?**

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**Aims:** Explore experiences of people with dementia and their bereaved informal carers during the last year of life and time surrounding death. Identify their underlying needs at this time. Inform local and national policy and practice in order to facilitate care that supports individual needs.

**Methods:** Qualitative methodology, unstructured interviews, field notes to supplement interpretation and analysis. Analysis informed by Grounded theory approach, supported by Nvivo 9, interviews recorded digitally and transcribed fully by the researcher. Participant feedback on inclusion was also sought to support planning of future projects.

**Results:** 40 interviews, mainly siblings or spouse, variety of backgrounds, age range 18-86 years. Most participants female (n=31), death occurred in various 24 hour care environments including district general hospitals, nursing and residential care homes. Four experienced death within family home. Five themes emerged from data; carers as experts; kindness, humanity and compassion in care; the hard work of caring; living and dying with dementia in the face of uncertainty and communicating in a world of chaos and unpredictability. Informal carers wish to collaborate and be included in all aspects of palliative and end of life care for their loved ones. Issues separating dementia from other life limiting illnesses and provision of palliative and end of life care are: disease course, uncertainty, unpredictability over long periods of time and the role of informal carers as experts with a group who have compromised communication skills.

**Conclusion:** If palliative and end of life care for this group is to mirror that provided for other terminal illnesses, development of knowledge, confidence and communication skills amongst the workforce is crucial. In order to be successful, multi agency working, flexible and creative ways of delivering palliative and end of life care for this group are essential.

**Abstract number:** OA80
**Abstract type:** Oral


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**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 Europe has changed over the last decades and whether trends differed in West and East European countries.

**Methods:** We analysed data from representative samples of 13 western European populations, for which data were collected in four consecutive waves of the European Values Survey (1981, 1990, 1999-2000, and 2008) and of 12 East European countries, for which data were collected in the last two or three waves. The main outcome measure of our study was the degree of acceptance of euthanasia, rated on a scale from 1 to 10.

**Results:** In general, a significant increase in acceptance of euthanasia was found in all West European countries across all waves, with the highest increase occurring in Belgium and Spain. In the Netherlands however, euthanasia acceptance stagnated over the last two waves (1999 and 2008). A opposite trend was found in Eastern European countries, with an overall decrease in euthanasia acceptance over the last two waves, except Hungary and Bulgaria. This decrease was particularly strong in the former Soviet states.

**Conclusions:** Over the last three decades a gradual increase of euthanasia acceptance among the general public occurred in Western European countries, whereas in Eastern Europe, an opposite trend was found. These findings may reflect the growing differences in public health between Western and
Central and Eastern Europe, as well as the revival of religion in a large part of post-communist Europe. Considering this polarization in euthanasia attitudes between West and East, a pan-European policy approach to the regulation of the issue will be extremely difficult, if not impossible.

Abstract number: OA81
Abstract type: Oral

A Comparison of the Incidence and Characteristics of Sedation Practice in the End-of-Life Care of Cancer Patients in UK Hospice and Hospital Settings
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Background: Most evidence about the practice of palliative or therapeutic sedation comes from surveys asking physicians to recall their practice and shows large unexplained variations in incidence across countries and care settings.

Aim: This study, which is part of the larger UNBIASED (UK Netherlands Belgium International Sedation Study) consortium, seeks to identify and compare the incidence and characteristics of sedation practice in the end-of-life care of cancer patients in UK hospice and hospital settings.

Methods: All adult cancer deaths in designated 12 week periods were identified in one hospice and one hospital (50% sample taken from the hospital). Patient characteristics, symptoms, types and duration of treatment and evidence of end of life decisions during the last week of life were identified, with attention to patterns of sedation with benzodiazepines (primarily midazolam) and/or levomepromazine or anaesthetic agents. Data were recorded onto a pro forma and analysed using SPSS.

Results: 61 people died of cancer in the hospice (male =34) aged from 25 to 86 years (mean 63 years). 57(93%) were prescribed midazolam; which was administered to 50 people (88%); 24 received continuous sedation via syringe driver until death (i.e.39% of total sample) ranging from 5 -40mg/24hours. In the hospital, 63 people were sampled (male=35) aged from 40 to 93 years (mean 72 years). 33(52%) were prescribed midazolam, 27(43%) received it in some form; 15 received continuous sedation via syringe driver until death (i.e. 24% of the total) ranging from 5 - 100mg/24hours.

Conclusion: Prescription and use of midazolam varied considerably between hospice and hospital. A majority of hospice patients were prescribed midazolam, compared to half of hospital patients. 2/5th of hospice patients but only a quarter of hospital patients had continuous sedation until death doses of which also varied. Further differences in practice will be presented.

Abstract number: OA82
Abstract type: Oral

Approaches to Suffering at the End of Life: A Qualitative Study of Sedation in the US and the Netherlands
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Objective: To study the experiences and perspectives of physicians from the Netherlands and the United States with respect to sedation in end-of-life care.

Design: Qualitative face-to-face interviews, purposive sampling. Thematic, interdisciplinary analysis.

Setting: Hospitals, nursing homes, and home care in the Netherlands and the US (Oregon and the Northeast)

Participants: 36 physicians (18 from the Netherlands, 18 from the US)

Measurements: Terminology used; situations in which sedation is used; physicians’ intentions; communication about sedation.

Results: In both countries physicians described a range of situations in which they used sedation. Its use was described in various terms, especially in the US, and was often experienced to be difficult and emotional. Physicians stated different and sometimes multiple intentions for their use of sedation, differentiating intentions from other effects the sedation may have. Besides alleviating severe suffering, most Dutch physicians justified the use of sedation by stating that it does not hasten death while most American physicians indicated that it might hasten death but that this was justifiable as long as that was not their primary intention. Many Dutch physicians considered the discussion of sedation an ongoing process and initiated open discussions about sedation pro-actively to inform patients about their options and to allow planning. American physicians seemed to have fewer and less open discussions, mostly late in the dying process with patients’ relatives.

Conclusion: Sedation is an important part of relieving suffering near the end of life. The legal and ethical framework of each society influences physicians’ views and practices of sedation. Clarification of practices and further research into effect and effectiveness of treatments will enhance informed reflection and ultimately our ability to relieve suffering.

Abstract number: OA83
Abstract type: Oral

Computer-based Symptom Assessment Is Well-accepted by Patients with Advanced Cancer

Assessment II

Abstract number: OA83
Abstract type: Oral

Computer-based Symptom Assessment Is Well-accepted by Patients with Advanced Cancer
Background: Electronic assessment of symptoms offers several benefits; i.e. easy data collection, storage and quality assurance, immediate presentation of scores, and tracking of symptoms over time. However, this is only effective if perceived useful for clinical use by patients and health care providers. Aims were to identify factors associated with discontinuation, time expenditure and patient preferences when using computers for symptom assessment in an international multi-center study; the EPCRC-CSA.

Methods: More than 1,000 advanced cancer patients were recruited from 17 centers in 8 countries. Patient self-report on pain, depression and physical function were entered directly on the laptops, supplemented by observer-based medical data.

Results: 965 patients (94.9%) with variable computer experience and a mean age of 62 years (SD 12.4) and mean Karnofsky score (KPS) of 71 (SD 16.3) completed the entire assessment. Predictive factors for non-completion were higher age, lower KPS and more pain (p-values ≤0.012). Time expenditure among completers increased with higher age, male gender, Norwegian nationality, comorbidity and lower physical function (p-values ≤0.007) but was inversely related to pain levels and tiredness (≤0.03). More than 50% preferred computerized assessment to paper and pencil version. Need for assistance was predicted by higher age, nationality other than Norwegian, lower KPS and lower education (p values < 0.001).

Conclusion: The high completion rate shows that computerized symptom assessment is feasible and acceptable in patients with advanced cancer. Future work should focus on identifying the minimum set of valid screening questions and refine the software to optimize assessment and reduce respondent burden in frail patients. Lower performance status reduces compliance and increases need for assistance. Whether symptom assessment should be performed by computers or on paper in the last stages of disease remains an empirical question.

Abstract number: OA84
Abstract type: Oral

Problems and Needs of Patients with Advanced Cancer in Indonesia and in the Netherlands

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Background: Cancer, particularly in advanced stages, is a disease with severe consequences for the quality of life. Comparing these consequences for patients in two countries with different cultures, climate and economic conditions may shed more light on universal or local consequences and needs for care.

Objective: To compare problems and needs of patients with advanced cancer in Indonesia and in the Netherlands.
Methods: We used a descriptive study of 274 advanced cancer patient to identify the differences between ‘problems and needs’ of advanced cancer patient in Indonesia and the Netherlands using the Problems and Needs in Palliative Care short version questionnaire (PNPC-sv). Chi-square analysis with Bonferroni correction was performed using SPSS 16.

Results: The prevalence of most physical problems was similar in both countries. In Indonesia, financial problems were the most common problems: Seventy-80% of the Indonesian study population experienced them versus 30-42% in the Netherlands. In the Netherlands, psychological and social problems were mentioned by 50-86%; these figures in the Indonesia were 25-50%. For each problem, the need for more care was much higher in Indonesia (>58%) than in the Netherlands (mostly <30%).

Conclusion: In both countries physical problems had about the same prevalence rates. Besides, non-physical problems were more prevalent than physical ones; in Indonesia all problems need more attention than in the Netherlands. Implication for practice: In both countries, non-physical problems were more prevalent than physical ones, more attention is needed for worldwide implementation of the WHO definition of palliative care, in which comprehensive cancer care is promoted. We advice to pay attention to as well physical problems, as to psychosocial, spiritual and other problems.

Abstract number: OA85
Abstract type: Oral

Evaluation of Using Observed Structured Clinical Examinations (OSCE) for Teaching, as Part of Cancer Care Education to 4th Year Medical Students in Leeds, UK

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Background: OSCEs are used in summative assessment in undergraduate and postgraduate education and have a wealth of supportive evidence. Their potential to provide feedback and highlight areas for development in formative assessment was suggested at its inception. This format of teaching mirrors assessment, something which has been shown to improve outcomes in summative assessments. Despite the advantages of using a ‘teaching OSCE’ (tOSCE) this method is under used.

Method: For the academic year 2010-2011 a tOSCE was introduced alongside standard teaching to 4th year medical students. It consisted of 5, 8 minute stations with real and simulated patients covering oncological emergencies, breaking bad news, history taking, radiotherapy complications and prescribing. Students rotated in groups of 4 or 5 around each station and received feedback (5 minutes). We collected written feedback from the students.

Results: Feedback was collected after 9 consecutive tOSCEs. 96% (190/196) were completed. 98% found it a useful way to learn and 99.5% agreed it covered relevant topics. The majority felt it; was interesting and enjoyable, 98%, highlighted gaps in knowledge and skills, 97%, helped prepare for assessment for progression, 96%, enhanced knowledge, 96%, increased motivation to explore subjects in greater depth, 94%, and was most useful because of immediate feedback, 94%. 14% felt it caused undue stress. Free text highlighted it as a positive experience and suggested its use in other teaching blocks. Ideas for improvement included increased length of time for and number of stations.

Conclusions: The tOSCE provided students with a positive and valued learning experience aligning outcomes, teaching methods and assessment. The format provided the students with small group teaching, peer learning and constructive feedback. For some students this format can be a cause of undue stress but the majority supported its use and suggested increasing time for this method of teaching.

Abstract number: OA86
Abstract type: Oral

The Effect Computer Based Clinical Decision Support Systems (CCDSS) on Patient Reported Outcomes (PRO) - A Systematic Literature Review

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Patient reported outcomes (PRO) are the main measurements in palliative care. Nowadays most patient records are electronic. Evidence Based Medicine is condensed in treatment guidelines (EBTG). EBTG in a computer based clinical decision support systems (CCDSS) may improve PRO. What is the content, outcomes and effect of CCDSS on PRO and how are they applied in medicine?

A systematic literature review in Medline and Embase with the following search strings was conducted: Computer (artificial intelligence, hospital information systems etc) AND PRO (Assessment, Quality of life (qol) etc) And Studies (clinical trial, comparative etc) Limits: 1996-2011, language English. Citations and abstract were screened by two independent reviewers. Disagreements were resolved consensually. Full text articles were retrieved for all potentially relevant articles. Snowballing was performed. Data was systematically extracted.
Hits(Medline 304, Emebase 226) 476 Records screened: 71. Full-text articles assessed: 18 Studies included: Patients: 22 154, Diseases: 5 Heart, 4 Lung, 3 Pain, 3 Mental, 3 General Trial design: 11 RCT, 2 Cohort, 2 Cluster, 3 Controlled. Interventions: 14 official guidelines, 3 in house decision support systems, 1 dosing recommendation. Application: 2 mail, 5 email, 7 documentation systems, 3 prescribing system, 1 case management program. Outcomes: 8 symptoms and qol, 5 symptoms only, 1 qol only, 1 physical activity, Data Collection time point: 5 days: 1, 45 days: 2, every 2 months: 2, every 3 months: 3, 6 months: 6, 12 months: 7 Effect: 2 positive, 4 some positive results, 12 negative. Application flow, time required and prompts to recommendations are key points.

There are marginal effects of CCDSS on PRO such as symptoms and overall qol. If CCDSS is to be applied in clinical practice and influence decision making, the content, design and integration in workflow needs to be improved. Implementation of guidelines in favor for the patient remains a challenge.

Abstract number: OA87
Abstract type: Oral

The Dyspnea Target/Opioid Responsiveness Score: Can a New Tool Help to Predict those Patients with Advanced COPD and Refractory Dyspnea who Would Most Likely Benefit from Opioid Therapy?

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Rationale: Some patients with refractory dyspnea appear to respond favorably to opioid treatment, others experience minimal benefit. A tool to predict which patients with COPD and refractory dyspnea respond favorably to opioids would be of value. We developed the Dyspnea Target/Opioid Responsiveness Score (ORS) and piloted it within a clinical trial designed to understand the experiences of those living with advanced COPD when opioids are added to usual therapy.

Methods: Patients completed the ORS at baseline and 4-6 months after starting opioids along with quantitative measures assessing dyspnea and health-related quality of life, at baseline, 2 months and 4-6 months plus degree to which opioids have helped (or not) on a 5-point Likert scale (5-LS). The ORS has 4 questions also 5-LS and assesses patients’ dyspnea related to their: 1) sense of fear, 2) perceived ability to control dyspnea intensity, 3) perception of dyspnea stability, and 4) ability to predict dyspnea onset. Scores were plotted on the dyspnea target. We hypothesized that patients with higher baseline ORS scores would be more likely to experience benefits associated with opioid therapy.

Results: 38 patients have enrolled and to date 20 have completed 6 months treatment. Results suggest most patients (75%) benefit from opioid therapy and confirm reduction in mean ORS at 4-6 months (8.50/20) vs. baseline (12.75/20) with the greatest reduction in dyspnea associated fear. Mean baseline ORS is lower for patients who withdrew (n=8, 10.63) vs. those completing the trial (n=20, 12.75). Individual domain analysis reveals that dyspnea associated fear is the most notable baseline difference between the two groups.

Conclusion: The “Dyspnea Target/Opioid Responsiveness Score” may help to predict those patients with advanced COPD and refractory dyspnea who would most likely benefit from opioid therapy. The perception of dyspnea related fear may be associated with a favorable response to opioids.

Abstract number: OA88
Abstract type: Oral

The ESAS as a Screening Tool of Depression in Palliative Care Cancer Patients

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Background: The Edmonton Symptom Assessment Scale (ESAS) is a widely used screening tool for symptoms in palliative care and includes two items on depression and anxiety assessed on 0-10 numerical rating scales. Major Depressive Disorder (MDD) is present in about 15% of palliative care cancer patients. If ESAS can correctly identify MDD, its clinical usefulness would be increased. Aims were to examine if the ESAS items on depression and anxiety can correctly identify MDD in cancer patients with advanced disease.

Material and methods: An international cross-sectional study assessing symptoms in palliative care cancer patients (the European Palliative Care Research Collaborative - Computerized Symptom Assessment Study (EPCRC-CSA)) was performed in 2008-2009. The ESAS was filled in as well as the Patient Health Questionnaire (PHQ). The PHQ assesses the criteria of a depression disorder according to the Diagnostic and Statistical Manual classification system (DSM-IV). Major
Depressive Disorder was defined by the DSM-IV criteria using the PHQ-scores.

**Results:** A total of 1051 patients were included of which 969 completed both questionnaires. The PHQ identified MDD in 133/969 patients (13.7%). The sensitivity and specificity of the ESAS depression-item as a screener for MDD were generally low. A cut-point of >=1 gave a sensitivity of 0.8 and a specificity of 0.5. A cut-point of >= 4 gave a sensitivity of 0.5 and a specificity of 0.8. The choice of different thresholds based on the ROC-curve will be discussed. Adding the anxiety item did not enhance the ability of the ESAS to correctly identify MDD.

**Conclusion:** The ESAS is not an optimal tool for screening for a Major Depressive Disorder in the palliative care setting.

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### Studying palliative care in dementia patients

**Abstract number:** INV27  
**Abstract type:** Invited Speaker  
**How Effective Is a Family Booklet about Comfort Care in Advanced Dementia? A Study in 3 Countries**  
**Arcand M.**  
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Most experts think that advanced dementia should be considered a terminal disease for which a palliative care approach is relevant. When medical complications occur, family caregivers are often required to participate on behalf of loved ones to difficult clinical and ethical decisions such as hospital transfers, management of feeding difficulties and of recurrent infections. Research has shown that many family members do not feel well prepared for this task and need support. Family education about progression of disease and the palliative/comfort care option has not been studied much. We have written a booklet entitled “Comfort Care at the End of Life for Persons with Alzheimer’s Disease or Other Degenerative Diseases of the Brain: A Guide for Caregivers”. Researchers in different countries, notably Italy, the Netherlands and Japan, have adapted its content to their own cultural and legal context. We have studied the acceptability of the booklet by professionals and family members and have found that it is generally well accepted and perceived as useful. The booklet can also be used as an educational tool for staff of long-term care institutions and a pilot study has shown an improvement in family satisfaction with care (especially communication about what to expect). A more definitive multifaceted intervention study with both staff training and family education has just started. The French and English versions of the booklet can be downloaded at [http://www.expertise-sante.com/guide_arcand_caron](http://www.expertise-sante.com/guide_arcand_caron)

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### References:


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**Abstract number:** INV28  
**Abstract type:** Invited Speaker  
**Nursing Home Residents Dying with Dementia in Flanders, Belgium: A Nationwide Post-Mortem Study on Quality of End-Of-Life Care and Quality of Dying**  
**Van den Block L., Vandervoort A., Deliens L.**  
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**Background:** There is a lack of nationwide data describing the circumstances of dying for people with dementia. We aimed to investigate quality of end-of-life care and quality of dying of nursing home residents with dementia in Belgium.

**Methods:** We conducted a post-mortem study (2010) using random cluster-sampling. In selected nursing homes, all deceased residents with dementia in a 3-month period were reported. For each case the nurse most involved in care, GP and nursing home administrator reported health status, clinical complications, end-of-life care, advance care planning and quality of dying using SM-EOLD, CAD-EOLD and QUALID. We used Cognitive Performance Scale and Global Deterioration Scale to assess dementia.

**Findings:** We identified 198 deceased residents with dementia in 69 nursing homes; 54% with advanced dementia. In the last month of life, 95% had one or more sentinel events eg eating/drinking problems, febrile episodes, or pneumonia. Most frequently reported symptoms were pain, fear, anxiety, agitation and resistance to care. In the last week of life, difficulty swallowing and pain were reported most frequently. Palliative care records were present for 62% of cases and a palliative care task group discussion took place in 49%. According to the GP, 9% had a written advance directive and for 76% a physician order limiting life-sustaining treatments was present, discussed with patients in 11% of cases. A legal representative was appointed in 6% of cases. At the end of life, one or more life-sustaining treatments were provided in 31% of cases.

Comparing different stages of dementia revealed few differences between groups.

**Interpretation:** Regardless of the dementia stage, many nursing home residents develop serious clinical complications in the last phase of life, posing major challenges to the provision of optimum end-of-life care. While half of the deceased residents develop to an advanced stage of dementia, advance patient directives are hardly present.
Studying end of life with dementia is challenging because of an ill-defined prognosis and frequent inability to self-report. In designing research, decisions on prospective versus retrospective data collection, process and outcome measures, and recruitment strategies are pertinent.

Prospective studies employ pre-death enrolment and data collection, whereas retrospective studies are limited to after-death data collection. Although generally less prone to biased associations, the collection of prospective data takes more effort per death assessment, as quantified with data of the Dutch End of Life in Dementia (DEOLD) study that employed the two designs in parallel. Further, prospective data collection usually involves right censoring because following all cases until death is often infeasible. This results in different, non-representative samples of decedents. Adjustment or stratification for dementia severity and length of stay, both of which also relate to outcome, is key in promoting comparability across studies. Process and outcome may be measured with instruments specific to dementia or mixed nursing home populations. However, some of the available instruments do not relate to the single concepts of quality of care (process), or quality of dying or satisfaction with care (outcome), which complicates interpretation of results. Properties of two of three End-of-Life in Dementia (EOLD) scales were better than those of other instruments in two parallel studies in the US and the Netherlands. Finally, recruitment strategies are critical. In the DEOLD study, when invited after death, families with more favourable end-of-life experiences were more likely to participate. The resulting response bias may be of particular concern in retrospective studies.

New studies may build-in the addressing of specific methodological issues. This will help researchers decide on the optimal design, and promote well-considered reporting on end of life with dementia and how to improve it.

Symptoms other than pain III

Prescribing Preferences for Nausea in Palliative Medicine

Abstract number: INV29
Abstract type: Invited Speaker

Studying End of Life in Dementia: Deciding on the Optimal Research Design

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Aim: Nausea can be a pervasive and problematic symptom for palliative care patients. Clinicians have a number of therapeutic options for the treatment of nausea. The choice of non-pharmacological or pharmacological options is clinician dependent. The aim of this national survey was to examine the prescribing preferences of palliative medicine clinicians for the treatment of nausea.

Methods: A cross-sectional online survey was sent out to Australian palliative medicine clinicians. Participants were presented with a clinical vignette about a patient with metastatic pancreatic cancer with continuous nausea. Participants were asked about the use of non-pharmacological measures, and the agent of choice for treatment of nausea, dosing and review schedules, maximum doses, and possible side effects. Participants were asked to offer the same information about their choice for second line treatment of the nausea.

Results: One hundred and five participants responded with 98 first and 98 second line treatment choices. Metoclopramide and haloperidol were the most common first line treatments, and haloperidol and dexamethasone the second line treatments, however in this group there was much larger variation in prescribing preferences. There were large variations in starting doses, time to review, and maximal doses. Metoclopramide starting doses varied by 10 fold and maximal doses by 8 fold (medians 30mg/day and 80mg/day respectively), whilst for haloperidol starting and maximal doses both varied by 10 fold (medians 1.0mg/day and 5mg/day respectively). The majority reviewed response by 48 hours.

Conclusion: There were large variations in prescribing for nausea amongst palliative care clinicians. Even for a single medication, the dosing was inconsistent. This highlights the need for well-designed studies of nausea treatment in palliative care patients to guide treatment choices and dosing.

Spirituality, depression and death

Abstract number: OA90
Abstract type: Oral

Aim: Depression is common in patients with advanced cancer but it can be difficult to clinically assess...
and manage. A large prospective study of patients with advanced cancer was established to determine the prevalence and progression of depression and demoralization.

**Aim:** This branch of the study aimed to explore if spirituality contributes to demoralization, depression and death.

**Study design:** Patients were recruited from hospice day care services and completed a set of baseline assessments including the Beliefs and Values Scale, and a sub-set at weeks 8, 16 and 24.

**Statistical analysis:** We analysed longitudinal correlation using Spearman’s coefficient of rank correlation and the association between spirituality and time to depression and death was analysed using Kaplan-Meier estimates and Cox proportional hazards modelling.

**Results:** 629 patients entered the study with a median age of 66 years, 32% with breast cancer, 25% with ECOG performance status >2, and median spirituality score at baseline of 54 (range 0-80). Low demoralization scores are strongly associated with spirituality over the period of the study. Spirituality is strongly negatively correlated with depression scores at baseline (p< 0.05), but these are not sustained over time to statistical significance. The estimated risk of depression is halved for patients who reported being a religious person relative to those who neither agree nor disagree with being religious (adjusted hazard ratio=0.5026, p=0.0245). Stronger spiritual beliefs are also associated with a lower risk of death: patients with high spirituality scores had an average reduction of 44% compared to patients with low scores (p< 0.05).

**Conclusion:** People with advanced cancer commonly express spiritual and religious beliefs and values and these may contribute to the way they cope with the impact of progressive disease. The therapeutic benefit of spirituality to patients warrants further investigation.

**Abstract number:** OA91

**Abstract type:** Oral

**The Effects of Acupressure on Fatigue of Lung Cancer Patients Undergoing Chemotherapy: A Double-blind Experimental Study**

**Tang W.-R.**

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This study aims to explore the effects of acupressure on fatigue of the lung cancer patients undergoing chemotherapy. It is a longitudinal double-blind experimental study. 57 subjects were recruited and randomly assigned to the experimental group (17: accept acupressure with essential oil; 24: accept pure acupressure) and the control group (16: accept sham acupressure). Hegu(LI4), Zusanli(ST36), and Sanyingjiao (SP6) were selected as the true acupoints and the metacarpal bone, the patella, and inner ankle as the sham acupoints. All subjects started the intervention from the first day of the initial chemotherapy. Subjects received one time of acupressure with each acupoint being pressed in rotation for 1 minute. Tang Fatigue Rating Scale, HADS, American Pain Society Patient Outcome Questionnaire-Pain Intensity Subscale, ECOG-PSR, and Pittsburgh Sleep Quality Index were used to measure subjects’ fatigue, depression and anxiety, pain intensity, physical performance status, and quality of sleep before the initial chemotherapy (T1), on the 3rd cycle (T2) and on the 6th cycle of chemotherapy (T3). Fisher’s exact test and ANOVA were used to analyze baseline data. In spite of age, there was no difference on basic information and disease severity level between groups. General estimation equation was used to determine whether subjects of different groups as measured at different time points have different levels of fatigue and relevant symptoms. After controlling age as the confounding variable, subjects who accepted acupressure with essential oil and those accepted pure acupressure had significantly lower fatigue, anxiety, and better physical function than the subjects accepted sham acupressure. The study results may serve as references to the management of fatigue symptom in patients with lung cancer undergoing chemotherapy.

**Abstract number:** OA92

**Abstract type:** Oral

**The Association between Inflammation and Fatigue Dimensions in Advanced Cancer Patients and Cancer Survivors**


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**Aim:** Inflammation may underlie cancer-related fatigue. However, there are no studies assessing the relation between fatigue and cytokines in patients with advanced disease versus patients without disease activity. Furthermore, the relation between cytokines and the separate dimensions of fatigue is unknown. Here, we explored whether levels of inflammatory markers were associated with physical fatigue and mental fatigue in advanced cancer patients (ACP) and cancer survivors (CS).

**Methods:** We included 45 ACP (no systemic anti-tumor therapy in the last month and no options for future therapy) and 47 CS (last treatment 1-5 years ago). Patients completed the subscales Physical Fatigue (PF) and Mental Fatigue (MF) of the Multidimensional Fatigue Inventory. We measured plasma concentrations of C-reactive protein (CRP), interleukin 1 receptor antagonist (IL1ra) and neopterin by ELISA and Interleukin 6 (IL6) and Interleukin 8 (IL8) by a Cytometric Bead Array. Differences in fatigue intensity and levels of inflammatory markers were determined using the Mann-Whitney test. Non-parametric
Results: Compared with CS, ACP had higher levels of PF (median 16 vs. 9, p<0.001) and MF (median 11 vs. 6, p=0.01). Levels of all cytokines were higher in ACP than in CS (p<0.01). 93% of ACP and 21% of CS had at least one marker above the upper limit of normal values (p<0.001). In the ACP, PF was correlated with CRP (r=0.49, p=0.001), IL6 (r=0.43, p=0.003), IL1-ra (r=0.32, p=0.03), and neopterin (r=0.25, p=0.10). No cytokines were related to MF in the ACP. In the CS, IL1-ra was related to both PF (r=0.24, p=0.10) and MF (r=0.35, p=0.02).

Conclusions: We showed that inflammation in the advanced cancer patients seems to be associated to physical fatigue, but not to mental fatigue. There was no convincing evidence that inflammation plays a major role in cancer survivors’ fatigue.

Abstract number: OA93
Abstract type: Oral

To Be Involved or Not to Be Involved - That Is the Question: A Population-based Survey of Preferences for End-of-Life Care Decision Making in Seven European Countries

Daveson B.A.1, Bausewein C.2, Murtagh F.E.1, Calanzani N.1, Higginson I.J.1, Harding R.1, Cohen J.3, Simon S.T.4, Deliens L.5, Bechinger-English D.1, Hall S.1, Koffman J.1, Ferriera P.L.6, Toscani F.7, Gysels M.8, Ceulemans L.9, Haugen D.F.10, Gomes B.1, PRISMA

1King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, London, United Kingdom, 2Deutsche Gesellschaft fuer Palliativmedizin, Berlin, Germany, 3End-of-Life Care Research Group Ghent University and Vrije Universiteit, Brussels, Belgium, 4University of Cologne, Center for Palliative Medicine, Cologne, Germany, 5VU University Medical Center and EMGO Institute for Health and Care Research, Palliative Care Expertise and Department of Public and Occupational Health, Amsterdam, Netherlands, 6University of Coimbra, Center for Health Studies and Research, Coimbra, Portugal, 7Fondazione Lino Maestroni (ONLUS), Cremona, Italy, 8University of Barcelona, Barcelona Center for International Health Research, Barcelona, Spain, 9University of Antwerp, Antwerp, Belgium, 10Norwegian University of Science and Technology, Trondheim, Norway

Aim: To examine public preference for involvement in end-of-life care decision making and associated factors in seven European countries.

Methods: A population-based telephone survey of a random sample of citizens ≥16 years in: England, Belgium, Germany, Italy, Netherlands, Portugal, Spain. Two dichotomous dependent variables regarding decision-making preferences were examined for capacity and incapacity scenarios each coded: involvement of self with or without involvement of others versus no involvement of self in decision-making. We used bivariate and multivariate analyses (generalised estimating equations).

Results: From 45,242 people approached, 9,344 participated (21%). Across countries, 73.7% preferred involvement when capable (59.9%-Portugal-90.8% Germany) and 43.9% preferred to be involved when incapable (17.9%-Portugal-83.3% Germany). The two most frequently selected answer options regarding who to involve were: self (73.7%) followed by spouse/partner (53.3%) when capable, and spouse/partner (61.9%) followed by other relatives (47.5%) when incapable. For capacity and incapacity scenarios (respectively), higher education levels (OR=2.77, 95%CI=2.15-3.57; OR=1.80, 95%CI=1.42-2.28), female gender (OR=1.27, 95%CI=1.14-1.41; OR=1.30, 95%CI=1.20-1.42), younger age (40-49 years OR=1.40, 95%CI=1.17-1.69; 50-59 years OR=1.23, 95%CI=1.04-1.46) and a valuing of quality over quantity of life were associated with a preference for involvement (OR=1.58, 95%CI=1.25-2.00; OR=1.53, 95%CI=1.23-1.91).

Conclusion: Nearly three out of four people from the general public across seven European countries want to be involved in making decisions when able. The public is divided about whether or not to be involved when unable to make decisions (for example involved in advance of becoming incapable). Patient choice and family involvement remains central to decision making. Identified factors associated with involvement require investigation.

Funder: European Commission.

Abstract number: OA94
Abstract type: Oral

A Natural History of Cancer-associated Cachexia

Baracos V.

University of Alberta, Oncology, Edmonton, AB, Canada

Background: Skeletal muscle wasting is considered the central feature of cachexia but the potential for skeletal muscle anabolism in patients with advanced cancer is unproven.

Objective: To investigate the clinical course of skeletal muscle wasting in advanced cancer and the window of possible muscle anabolism.

Design: Quantitative analysis of computed tomography (CT) images for loss/gain of muscle in population-based cohorts of advanced cancer patients (lung, colorectal, pancreas cancer, cholangiocarcinoma) was conducted.

Results: Advanced cancer patients (n=388, median survival 196 d) had a total of 1279 CT images over the course of their disease. While muscle loss was common, the overall frequency of muscle gain was 15.4% and muscle was stable in 45.6% of intervals between any 2 scans.
Multinomial logistic regression revealed that being within 90 d (vs > 90 d) from death was the principal risk factor for muscle loss (OR=2.67, p=0.002) and muscle gain was correspondingly less likely (OR=0.49, p< 0.009) at this time. Sex, age, Body Mass Index and tumor group were not significant predictors of muscle loss or gain.

Conclusions: Cancer patients within 90 d of death are characterized by intense muscle loss and low likelihood of muscle gain. A window of anabolic potential exists earlier within the disease trajectory and may be an opportune time for randomized clinical trials of emerging new interventions that stop or reverse cachexia. The population-based frequency of gain/stable/loss muscle behavior provides a useful benchmark, permitting preliminary identification of drugs that require further investigation of their potential to exacerbate or limit muscle loss.

Plenary session III

Abstract number: INV30
Abstract type: Invited Speaker

Dying At Home - Is It Better: What We Have Learned and Where Are We Going?

Higginson I.J.

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

‘Home is the place where it feels right to walk around without shoes’

For many people, home is more than a physical space. It represents the possibility of enjoying ‘normal life’, the presence of loved ones and familiarity. It features in artistic works, for example, the hymn ‘Going Home’ set to Dvořák’s 9th symphony. In the past decade there has been growing concern about the gap between preferences and reality in where people die, with a view to improving choice and the adequacy of planning care for terminally ill patients. Although in many countries about two thirds of people prefer to die at home, dying has become increasingly institutionalised in most developed and developing world regions. This presentation will consider:

1. National and international trends and future predicted trends in place of death.
2. The relationship between place of care and place of death.
3. What does home mean? What places can be considered as home and what not?
4. What are the preferences for patients and families regarding home death? How important is it? Do preferences vary between groups and over time?
5. What factors are associated with home care and home death? Is this different in different groups of people?
6. Is home care or home death better? For whom and when?

The presentation will draw on empirical evidence and systematic literature reviews. It will consider the future clinical, policy and research actions needed to more closely meet patients’ and family members’ preferences regarding place of care and place of death in advanced illness.

References:
Gomes B et al., Pall Medicine 2012, 18 Jan. PMID 22258367

Abstract number: PL5
Abstract type: Plenary

Variability in UDP-Glucuronosyltransferase Genes and Morphine Metabolism. Observations from a Cross-Sectional Multicenter Study in Advanced Cancer Patients with Pain

Fladvad T.1, Klepstad P.1,2, Langaa M.3, Dale O.1,2, Kaasa S.1,4, Caraceni A.5, Skorpen F.1

1Norwegian University of Science and Technology (NTNU), European Palliative Care Research Center (PRC), Trondheim, Norway, 2St. Olav University Hospital, Department of Anaesthesiology and Emergency Medicine, Trondheim, Norway, 3Norwegian University of Science and Technology (NTNU), Department of Mathematical Sciences, Trondheim, Norway, 4St. Olav University Hospital, Department of Oncology, Trondheim, Norway, 5Pain Therapy and Rehabilitation Unit, Fondazione IRCCS Istituto Nazionale Tumor, Palliative Care, Milan, Italy

Introduction: The morphine dose needed to obtain pain relief varies considerably between individuals. Morphine is glucuronidated by members of the UDP-glucuronosyltransferase (UGT) family, mainly UGT2B7, UGT1A1 and UGT1A8, to a 6-conjugate (M6G) with analgesic efficacy and a 3-conjugat (M3G) with no analgesic potential. It is not established if genetic variability in genes encoding these enzymes influences morphine glucuronidation. The aim of our study was to establish if known variability in these genes contributes to the variation in morphine metabolism in cancer pain patients.

Methods: 865 patients who were included in a cross-sectional, multicenter study on opioid pharmacogenetics who received morphine for cancer pain were included. Morphine, M6G and M3G serum concentrations were determined and 41 polymorphisms in the UGT2B7, UGT1A1 and UGT1A8 genes were analyzed. Multiple linear regression analyses including clinical and genetic factors were performed to decide which factors that predicted the ratios between morphine and metabolites.

Results: The patients’ mean age was 62.6 ± 11.9 years, 53.5% were males and the mean morphine dose was 127.1 ±
176.27 mg/24h. For oral morphine the use of paracetamol, liver metastasis, age, BMI, renal function, time from last dose to blood sampling, gender, Karnofsky performance score and homozygosity for a common haplotype in the \textit{UGT1A1} gene were associated to variability in M6G/morphine ratio. The model explained 41% of the variability in the data. The model for variability of M3G/morphine ratio was in general similar to that for M6G/morphine ratios.

**Conclusion:** In addition to clinical factors also genetic variability in the \textit{UGT1A1} gene contribute to variations in morphine metabolism in cancer pain patients.

The Norwegian Research Council, the European Union’s 6th framework (Contract No. 037777) and The Liaison Committee between the Central Norway Regional Health Authority (RHA) and NTNU financially supported the study.

**Abstract number:** PL6

**Abstract type:** Plenary

**Needs Concerning Fatigue among Patients with Advanced Cancer in Denmark; A Cross Sectional Survey**

\textit{Madsen U.R., Johnsen A.T., Groenvold M.}

Bispebjerg Hospital, The Research Unit, Department of Palliative Medicine, Copenhagen, Denmark

**Aims:** To investigate needs for help concerning fatigue in a nationally representative sample of Danish advanced cancer patients. We explored the relationship between having fatigue, perceiving fatigue as a problem and experiencing need for help concerning fatigue.

**Method:** A cross sectional survey taken place 2004-05 among advanced cancer patients in Denmark (all diagnosis incl. haematological ex. skin cancer). In total 1447 filled in the questionnaire (61%). They were asked about their needs concerning fatigue at three different levels; 1. Symptom intensity (using EORTC QLQ-30 fatigue scale) 2. Problem burden (using the item from The Three-Levels-of-Needs-Questionnaire (3LNQ) measuring if fatigue has been perceived as a problem) 3. Felt need (using the item from 3LNQ measuring whether the patients experience that they have received adequate help).

**Results:** In total 57% report having fatigue as symptom (score $\geq 33$ on a 0-100 scale) 73% having fatigue as at least “a little” problem, 22% report having fatigue as a severe symptom (score $\geq 66$ on a 0-100 scale) 36% having fatigue as at least “quite a bit” of a problem. There is a high correlation between having fatigue as a symptom and fatigue as a problem (Spearman 0.85): the higher the symptom the more a problem. In the felt need item 36% report having received inadequate help and therefore have an unmet need for help, 9% report no wish for help, and only 15% report having received adequate help. There is a moderate correlation between felt need and problem burden (Spearman 0.52) the more fatigue is perceived as a problem the more likely the patient is to have an unmet need.

**Conclusion:** Between 22% and 73% of the sample had a need concerning fatigue depending on the measuring approach. The tree levels of needs were moderate/high correlated. However, it seems that even a little fatigue is a problem to the advanced cancer patient, and some patients report having an unmet need, despite experiencing fatigue as a smaller problem.
Abstract number: P1
Abstract type: Poster

Symptom Prevalence & Management of Cancer Patients in Lebanon

Abu-Saad Huijer H.
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Aim: Cancer patients experience a great number of distressing physical and psychological symptoms. In Lebanon, there are no available data on symptom prevalence and symptom management in adults with cancer. The aim of this study was to determine the prevalence of symptoms and the effectiveness of treatment received as reported by patients.

Methods: The study used a cross-sectional descriptive survey design. The European Organization for Research and Treatment of Cancer-Quality of Life Questionnaire (EORTC-QLQ C-30) and the Memorial Symptom Assessment Scale (MSAS) were translated to Arabic and used; data were collected from adult Lebanese cancer patients at the American University of Beirut-Medical Center.

Results: A total of 200 cancer patients participated in the study; the majority was female with breast cancer and mean age 54. The cognitive functioning domain of the Quality of Life scale was found to have the highest score and social functioning the lowest. The most prevalent symptom was lack of energy. Nausea and pain were the symptoms mostly treated. Males reported better quality of life, physical functioning, and role functioning than females; females reported more fatigue, pain, and appetite loss than males. Higher physical and psychological symptoms were correlated with lower health status, quality of life, and functioning.

Conclusion: Although this sample reported a fair quality of life and social functioning, many symptoms were highly prevalent and inadequately treated. Symptoms were found to negatively affect quality of life and functioning. Based on these results, providing adequate symptom management and social support to Lebanese cancer patients is highly recommended.

Abstract number: P2
Abstract type: Poster

Assessment and Management of Chronic Pain in Renal Transplant Patients

Leiva-Santos J.P., Sánchez Hernández R., Larraya G., Fernández-Reyes M.J.
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Introduction: Little is known about chronic pain and long-term impact on renal transplantation (RT).

Objectives: To study the prevalence of pain, clinical and psychological risk factors associated with pain, and treatment and analgesic response in recipients of RT.

Methods: Prospective, and interventional study in 101 patients with effective RT. Clinical, laboratory and radiological variables were analyzed. The following scales were used: Brief Pain Inventory-Short Form, Hospital Anxiety and Depression Scale, Short Portable Mental Status Questionnaire and the Palliative Performance Scale (PPS). Statistical analysis was performed with SPSS v.0.18.

Results: We studied 101 patients with mean age of 59.3 years, 65.3%♂ and 46% of the population presented pain. The highest intensity mean of pain was 7/10 points and the lowest was 4/10. Of the total 25% had analgesia prescribed previously and only reported relief of intensity in 30%. Anxiety in 14% and depression in 8%. PPS calculated for 88% of patients was 90-100 points and 96% had no cognitive impairment. Patients with pain showed a higher incidence of bone mass loss (BML), gastro-intestinal disease and greater use of steroids and calcineurin.

Univariate correlations showed a statistically significant correlation between quantified pain and the following variables: use of steroids and calcineurin inhibitors (p<0.0001; p = 0.027 respectively), BL (p<0.0001) and gastrointestinal disease (p=0.032). In a multivariate analysis, the only factors that were independently correlated with quantified pain were steroids (ExpB: 9.171, CI: 2.602-32.328; p = 0.01) and BML (ExpB: 6.527, CI: 2.049-20.788; p = 0.032). Pain occurred regardless of the stage of disease.
Conclusions: About half of the patients with successful kidney transplant suffer from chronic pain, mainly associated with steroid treatment and BL. Analgesic treatment in this population is underused, and chronic pain in transplanted patients is understudied.

Abstract number: P3
Abstract type: Poster

What Do Patients with Advanced Incurable Cancer Want from the Management of their Pain?
Gibbins J., Bhatia R., Forbes K., Reid C.
Universities of Bristol NHS Foundation Trust, Palliative Medicine, Bristol, United Kingdom

Aims: Pain is one of the most frequent symptoms among patients with metastatic cancer. Measuring the efficacy of the management of pain is challenging. There is currently little in the literature to inform us how patients with advanced incurable cancer determine whether their pain is controlled or not. This study aimed to explore how these patients describe the control of pain.

Methods: A qualitative study using face-to-face interviews with patients who had advanced incurable cancer and experienced pain. Data were analysed using the principles of the grounded theory approach.

Results: Twelve patients were interviewed until data saturation was reached; four themes emerged; 'maintaining role, self and independence', 'compromising/modifying expectations', 'role of healthcare professionals' and 'meaning of pain in context of illness'.

Conclusion: Patients determined if their pain was 'controlled' by whether or not they were able to perform activities or tasks, and maintain relationships with family or friends, which determined themselves as individuals. Participants did not find the use of numerical rating scales useful or meaningful in determining whether they were able to perform these activities or maintain a sense of control and independence. Goal setting for patients with advanced cancer pain may be useful to allow patients to determine what they want from the 'management' of their pain. These patient derived outcomes could be useful in clinical practice and research.

Abstract number: P4
Abstract type: Poster

Adjuvant Switch from Gabapentin to Ketamine for Neuropathic Cancer Pain in Terminal Patients
Takigawa C., Suzuki T.
1KKR Sapporo Medical Center, Palliative Medicine, Sapporo, Japan. 2KKR Sapporo Medical Center, Palliative Care Team, Sapporo, Japan

Aims: Intractable pain is a management problem for cancer patients. Gabapentin is used widely for treating neuropathic pain. Terminal patients easily lose their oral intake ability. Ketamine, an NMDA receptor antagonist, has been available in subcutaneously and intravenously forms. Its usefulness in intractable pain as an adjuvant to opioids is well-known. The aim of this study was to evaluate the efficacy and safety of switching from gabapentin to ketamine for neuropathic pain in terminal patients who were unable to orally take medications.

Methods: In this retrospective study from January 2010 to June 2011, 14 neuropathic cancer patients were switched from gabapentin to ketamine due to disability of oral intake in the palliative care ward in KKR Sapporo Medical Center. Patients charts were checked
1) gender
2) age
3) the dose of gabapentin before switch
4) the dose and the duration of ketamine administration after switch.

The effectiveness for symptoms (pain, numbness, sleepiness, depression) were evaluated by a Japanese version of the Support Team Assessment Schedule (STAS-J) and Pain was scored by Numerical Rating Scale (NRS). Adverse events were also evaluated.

Results: Mean duration of ketamine administration was 28 days, initial dose of ketamine was 42mg, the maximum dose of ketamine was 95mg. Pain score by NRS were 2.8 (before switch) to 2.2 (after switch), numbness by STAS-J was 1.8 to 1.4. Sleepiness was improved by STAS-J 3.0 to 1.8 significantly. Depression scored by STAS-J was changed 2.1 to 1.6. As for adverse effect, a short term headache and dizziness (STAS 1) was observed for one patient.

Conclusion: Ketamine is a useful adjuvant for neuropathic pain when switching from gabapentin in terminal patients. We need to verificate ketamine's clinical usage in prospective study.

Abstract number: P5
Abstract type: Poster

Tumor Pain Management by Physicians in Rural Areas
Sternfeld T., Birkemeyer E., Vehling-Kaiser U.
Onkologisches und Palliativmedizinisches Netzwerk Landshut, Landshut, Germany

Background: Guidelines for the treatment of pain in oncology and palliative care have been published. However, data regarding the implementation of pain management in clinical reality are lacking. The Landshut Network for Oncology and Palliative Care (ESMO Designated Center of Integrated Oncology and Palliative Care), situated in a rural region of Lower Bavaria (Germany), aims to improve the pain management in tumor patients. Pain treatment
in rural areas is mainly performed by patients’ general practitioners. In these areas, specialists are rare and the distances to specialized centers are long compared to the situation in large cities.

**Methods:** To get an insight into the practice of pain therapy, a standardized questionnaire was sent to 287 general practitioners caring for tumor patients in a rural region of Lower Bavaria. The questionnaire contained questions about twelve items, e.g. the number of treated pain patients, the use of analgesics, oral opioids, fast acting opioids, and pain pumps, the percentage of patients with breakthrough pain, the management of breakthrough pain, the percentage and reasons for switching analgesics prescribed from the hospital. The questionnaire was sent to all the physicians simultaneously in June 2011. Data collection and analysis was anonymous, it was performed in September 2011. Physicians who had completed the questionnaire received a financial compensation of €20.

**Results:** We will present the first data analysis of the survey. The retrieval rate was 43% (124/287). Data for all items will be presented in detail. The differences found regarding the perception and management of breakthrough pain in physicians’ practice compared to literature and current guidelines will be discussed.

**Abstract number:** P6

**Abstract type:** Poster

**The Effectiveness of Patient Pain Education Combined with a Pain Consult in Improving Medication Adherence: A Randomized Controlled Trial**

Oldenmenger W.H.1, de Raaf P.J.1, Sillevis Smitt P.A.2, van der Rijt C.C.1

1Erasmus MC, Medical Oncology, Rotterdam, Netherlands, 2Erasmus MC, Neurology, Rotterdam, Netherlands

**Background:** Pain Education Programs (PEP) and a Pain Consult (PC) have been studied to overcome patient and professional barriers in cancer pain management. These interventions were only studied separately, with several methodological flaws. Only 3/18 previous studies found a significant effect of PEP on medication adherence. In a randomised controlled trial (RCT) we previously found the combination of PC&PEP to be more effective in decreasing pain than Standard Care (SC). In this secondary analysis of the RCT, we evaluated the effect of combined PC&PEP on oncology outpatients’ adherence to their analgesic regimen during the 8-week study period.

**Methods:** During the study, adherence was measured with the Micro-Electronic Monitoring System (MEMS). The MEMS consists of a medicine container with an electronic circuitry that registers when the lid is opened. Adherence was defined as ‘taking adherence’ (% of total prescribed analgesics taken), and ‘timing adherence’ (% prescribed doses taken on schedule). Mean adherence was measured in the time intervals: week 1&2; week 3&4; and week 7&8. Between-group differences per time interval were analysed using non-parametric tests. The study protocol was approved by the Institutional Review Board of the Erasmus MC.

**Results:** We included 72 patients, mean age 59 years (sd=11), 65% female. At baseline, the groups were similar with respect to performance, tumour type and pain related outcomes.

<table>
<thead>
<tr>
<th>Time point</th>
<th>SC (n=37) (%)</th>
<th>PC&amp;PEP (n=35) (%)</th>
<th>p-value</th>
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<td>Timing adherence</td>
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<td>Week 3&amp;4</td>
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<td>Week 7&amp;8</td>
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**Conclusions:** The combined intervention significantly improved patients’ adherence to their analgesics. More attention should be given to stress the importance of taking analgesics on schedule.

**Abstract number:** P7

**Abstract type:** Poster

**Implementation of the Dutch Clinical Practice Guideline Pain in Patients with Cancer: A Clustered Randomised Controlled Trial with Short Message Service (SMS) and Interactive Voice Response (IVR)**

te Boveldt N.D., Engels Y., Besse T.C., Vissers K.C.P., Vernooij-Dassen M.J.F.J.

UMC St Radboud, Anesthesiolgy, Pain and Palliative Care, Nijmegen, Netherlands

**Background:** Half of patients with cancer have pain. In nearly one out of two cancer patients with pain, this was undertreated. Inadequate pain control still remains an important problem in this group of patients. Therefore, in 2008 a national, evidence-based multidisciplinary Clinical Practice Guideline (CPG) “pain in patients with cancer” has been developed. Yet, publishing a guideline is not enough. Implementation is needed to improve pain management. An innovative implementation strategy, Short Message Service with Interactive Voice Response (SMS IVR), has been developed and pilot tested. This study aims to evaluate this strategy, with technical tools, an active role of the patient and involvement of caregivers in primary and secondary care.

**Background:** Pain Education Programs (PEP) and a Pain Consult (PC) have been studied to overcome patient and professional barriers in cancer pain management. These interventions were only studied separately, with several methodological flaws. Only 3/18 previous studies found a significant effect of PEP on medication adherence. In a randomised controlled trial (RCT) we previously found the combination of PC&PEP to be more effective in decreasing pain than Standard Care (SC). In this secondary analysis of the RCT, we evaluated the effect of combined PC&PEP on oncology outpatients’ adherence to their analgesic regimen during the 8-week study period.

**Methods:** During the study, adherence was measured with the Micro-Electronic Monitoring System (MEMS). The MEMS consists of a medicine container with an electronic circuitry that registers when the lid is opened. Adherence was defined as ‘taking adherence’ (% of total prescribed analgesics taken), and ‘timing adherence’ (% prescribed doses taken on schedule). Mean adherence was measured in the time intervals: week 1&2; week 3&4; and week 7&8. Between-group differences per time interval were analysed using non-parametric tests. The study protocol was approved by the Institutional Review Board of the Erasmus MC.

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**Conclusions:** The combined intervention significantly improved patients’ adherence to their analgesics. More attention should be given to stress the importance of taking analgesics on schedule.
Methods/design: A randomised controlled trial with two arms will be performed in six oncology outpatient clinics of hospitals in the South eastern part of the Netherlands, with three hospitals in the intervention and three in the control condition. Follow-up measurements will be conducted in all hospitals, to study the long-term effect of the intervention. The intervention includes training of professionals (medical oncologists, nurses and general practitioners (GPs)) and SMS IVR to report pain in patients with cancer to improve pain reporting by patients, pain management of medical oncologists, nurses and GPs, and decrease pain intensity.

Discussion: This innovative implementation strategy with technical tools and the involvement of patients, might enhance the use of the guideline pain in cancer patients. SMS IVR alerts might serve as a tool to support self-management of patients. Therefore, the SMS IVR intervention might increase the feeling of having control over one’s life. Trail registration: This study is registered as a Clinical Trial in Dutch Trial Register, dossier number: NTR2739.

Keywords: Cancer, pain, pain management, SMS/IVR, implementation.

Abstract number: P8
Abstract type: Poster

Breakthrough Pain (BTP) in Terminal Stadium of Cancer Diseases

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The objective was to determine the incidence of breakthrough pain in patients whose primary basal cancer pain was treated with transdermal fentanyl and oral morphine.

Examinees and the methods: 80 patients, who were hospitalized in Palliative Care Center of PHI Clinical Center Tuzla, were examined. Those patients who had severe cancer pain (rating from 7 - 10 according to NRS) were treated with severe opiates - TD fentanyl (experimental) and with oral morphine (control group). The breakthrough pain is treated as “The Dose of Rescue” using oral morphine (8 mg). The next 10 days, are recorded daily: the frequency, time of occurrence and duration of pain breaking through.

Results: Number of breakthrough pain in patients of experimental group, compared to patients in the control group was statistically significantly higher first (p = 0.001) and second day, but most with no statistically significant difference of the third, fourth, fifth and sixth days of treatment. Conversely, patients within a control group, significantly higher number of BTP was recorded on the seventh, eighth and ninth day (p = 0.03) of the treatments. 55.3% of BTP appeared in the evening and night hours, and 44.70% in the period 06-18 hours (p < 0.0001). The average duration of breakthrough pain was 15, 51 minutes; 38, 25% between 16 and 20 minutes. 33, 67% of breakthrough pain was less than 10 minutes (p = 0,013) and 17, 91% between 21 and 30 minutes.

Conclusion: Oral morphine shows better efficiency in comparison to TDF in titration phase therapy, while there is less breakthrough pain in patients treated with TDF in the last trimester of the treatment (7 to 10 days).

Keywords: Breakthrough pain, morphine, transdermal fentanyl.

Abstract number: P9
Abstract type: Poster

 Patients’ and Family Caregivers’ Experiences with a Self-management Intervention for Cancer Pain

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Aim of the study: Pain self-management is a critical issue for patients with advanced cancer. However, implementing adequate pain self-management strategies is considered a major barrier to optimal pain control. In a single-center randomized controlled pilot study, an intervention designed to improve cancer pain self-management was tested regarding its ability to reduce pain. The aim of this qualitative sub study was to explore patients’ and family caregivers’ (FCs) experiences with pain management, with the intervention, and their view of burden and benefit from study participation.

Methods: For the main study, 39 adult oncology outpatients with advanced cancer were randomized to receive the intervention or an “attention intervention.” The intervention included 6 visits and 4 phone calls over 10 weeks and was based on 3 key strategies: provision of information, skills building, and ongoing nurse coaching. After completion of the main study, interviews were conducted with 9 patients and 4 FCs of the intervention group. Interviews were analyzed using qualitative content analysis.

Results: Patients and FCs gained new knowledge regarding pain and pain medication, including opioids. Their abilities to self manage pain improved. They appreciated the clear focus on their needs and valued a trusting relationship to the competent intervention nurse, the amount of time she spent...
Abstracts

with them, and her caring attitude. However, they never contacted the nurse between visits. The pain diary was seen as useful; some patients planned to use it further. Visits and phone calls were well accepted, while study questionnaires were burdensome for several patients.

Conclusions: Patients with advanced cancer and FCs considered an intervention that included provision of information, skills building, and ongoing nurse coaching as useful to improve pain self management.

Funding sources: Ebnet Foundation, Parrotia Foundation, Stiftung zur Krebsbekämpfung, hans-h. hasbargen GmbH & Co.KG

Abstract number: P10
Abstract type: Poster

Type of Pain in a Cohort of Cancer Patients

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Background: Cancer pain can be determined by multiple causes: directly from tumor (70%) from antineoplastic therapy (20%) but in 3-10% of the cases, even if associated with the disease, it does not depend on therapy.

Scope: To evaluate prevalence and impact of various types of pain in a population of cancer patients in order to optimize management of pain and frequency of administration of the category of used drugs.

Methods: Starting 2009 till 2011, 230 pts diagnosed with cancer came under observation (age:29 to 85 years, mean:60.1, median 61 years, DST:14.2) out of them 139M (60%, median age 59 y) and 91F (40%, median age 69 y) with varying degrees and intensity of pain. Pain measured through VAS, Pain Score, Drug Score and classified by type (somatic, neuropathic, mixed) and origin (tumor, iatrogenic, from other causes) in relation with history and clinical examination.

Results: Pain was directly caused by tumor in 67.8%, 19.7% by treatment, 12.5% by other causes. As for intensity, it was found to be slight (VAS:1-4) in 27% of pts; mild to moderate (VAS:4-6) in 42% of pts; moderate-severe (VAS:6-10) in 31% of pts. In relation to VAS assessment, NSAIDs, selective COX-2 inhibitors, minor opioids and/or major opioids, have been used in combination with adjuvant drugs. No correlation was observed between type and source of pain (p=0.211), and no significant differences between severity of cancer pain and iatrogenic pain have been observed (VAS:p=0.347; Pain Score:p=0.137). On the other hand, from the comparison of class of used drugs and frequency of administration, a decreased use of drugs has been observed for the iatrogenic pain (Drug-Score:p=0.01).

Conclusions: Based on our results, non-neoplastic pain showed a high prevalence, iatrogenic pain (perhaps because it was less drug-treated) was similar for gravity to the tumor sourced one. The latter was recorded with high prevalence in general and specifically, respectively in pts with tumors of the head and neck and in those with bone metastases.

Abstract number: P11
Abstract type: Poster

Chronic Pain and Health-related Quality of Life in Danish Cancer Patients and Survivors

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Aim: The aim of this study is to examine health-related quality of life according to chronic pain and status of cancer disease in a national representative survey.

Methods: The survey (Danish Health Survey 2010) was based on random sample of 25,000 individuals (≥16 y). In all, 60.7% completed a mailed or online questionnaire, which included items on e.g. chronic pain (≥6 mo), socio-demographics, self-rated health and health-related quality of life (SF-12, v.2, 2 subscales: Mental Component Summary - MCS and Physical Component Summary - PCS). The sample in the present study is restricted to individuals ≥ 50 y.

Results: In this study, 6,380 subjects were analyzed, from which 159 had current cancer and 536 were cancer survivors. The prevalence of chronic pain was higher among current cancer patients (48.7%) than among cancer survivors (41.5%) and individuals with no cancer history (33.0%). Current cancer patients also had worse scores on SF-12 and self-rated health. No differences in mean MCS or PCS scores were found between cancer survivors and persons with no cancer history when stratifying for chronic pain. Among persons reporting chronic pain, there was no difference in the proportion of persons who rated their health as excellent, very good or good between cancer survivors (sex- and age adjusted percentage: 63.2%) and persons with no cancer history (58.9%) (p=0.16). Furthermore, regarding self-rated health the analyses showed that there was no difference between current cancer patients without chronic pain (59.5%) and individuals with chronic non-cancer pain (58.9%) (p=0.30).
**Conclusion:** Patients with cancer were more likely to have chronic pain, worse health-related quality of life and self-rated health status. Nevertheless, survivors had equivalent quality of life and health compared to subjects without cancer history. Chronic non-cancer pain seems to influence quality of life and health in a very similar way as cancer disease.

**Abstract number:** P12  
**Abstract type:** Poster  
**Lidocaine Patch (LP) as an Effective Short-term Co-analgesic in Cancer Pain: Preliminary Results**  
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**Background:** Pain from tumors involving chest wall or from scar tissue following mastectomy or thoracotomy is a common, difficult to manage, cause of neuropathic and mixed pain. There are very few reports of the use of the LP in cancer pain.

**Aim:** To evaluate the short-term efficacy and patient perception of LP in patients (pts) with painful scar (PS) or thoracic wall tumor involvement (TWTI) in a palliative care service of a comprehensive cancer centre.

**Material and method:** Open-label, uncontrolled study. The study population included outpatients with uncontrolled pain from either PS or TWTI. Pain, current medication (Morphine Oral Equivalent Daily Dose MEDD; co-analgesics) and need of Interventional Anesthetic Techniques (IAT) for pain control were assessed at baseline and within the 3rd and 6th weeks. Patients were assessed for pain alleviation (verbal rating scale VRS), global satisfaction (3 points ordinal scale) and adverse effects. Comparative data analysis was performed with non-parametric tests.

**Results:** Twenty pts (55% men) mean age 62 years old were included. A clinically-relevant and statistically significant improvement in all pain parameters was observed (average pain decreased from 5.2 to 3 in the VRS; \(p<.05\) and also the number of breakthrough pain daily episodes from 3.2 to 1.7; \(p<.05\)). Opioid escalation during the study period was not clinically relevant (125mg MEDD at baseline to 139mg at the end of the follow up). Mean MEDD in the PS group was 48mg, and TWTI group was 164.2mg. Only 3 pts required IAT for pain control. Most pts (65%) were very satisfied, 20% reported a slight improvement and 15% reported no pain improvement. No systemic or local adverse events were reported.

**Conclusions:** The addition of LP as a co-analgesic in pts with PS and TWTI provides short term clinically-relevant pain relief, satisfaction and it was safe and well-tolerated.

**Access to Opioids in Two Regions of Russia**  
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**Background:** The development of hospice care in Russia is making slow and difficult progress. Adequate pain management is still a major concern. Only injectable opioids (Morphine, Promedol), sustained release Morphone tablets, and Fentanyl in transdermal patches are available for the treatment of severe pain in the country.

**Aim:** What types of analgesics for severe pain are available at two hospices in the separate Regions of Russia?

**Method:** A case study approach was employed to assess opioid therapy at the Kemerovo Regional Hospice (KRH) and at the Ulyanovsk Regional Hospice (URH). To conduct the study, the authors reviewed 50 cases from each hospice.

**Results:** The majority of patients admitted to each of the hospices had severe pain: 70% at KRH and 46% at URH. At both hospices, the majority of patients with severe pain were admitted for the first time (76% at KRH and 86% at URH). MST-Continus in various doses and Fentanyl patches were employed for pain management for 92% of patients at KRH. 23 out of 34 patients (68%) with severe pain received MST-Continus and 13 of them (38%) received it in a dose of 60 mg a day. 8 patients (24%) were treated with Fentanyl patches and 4 of them (50%) received the 25 mcg/hour-dose patches. Only injectable opioids were employed at URH for pain management for all patients (100%) with severe pain.

**Conclusion:** Regional administrations are ultimately responsible for implementation of health care in their regions. Both hospices, KRH and URH, receive their operating budgets from their respective Regional administrations. Short acting Morphine tablets are not available in Russia. The costs of modified-release formulations of opioids are expensive, although the Russian Ministry of Health and Social Development controls the prices of medications on the List of Essential Medicines. Therefore, the financial restraints of the Regional administrations that set the budgets for KRH and URH define the availability of adequate pain control.
Abstract number: P14
Abstract type: Poster

Genetic Variation in Opioid Receptor Genes and Sensitivity to Experimental Pain in Male and Female Healthy Volunteers

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Introduction: Pain is a common problem which significantly impacts on quality of life. Clinical pain is complicated to study due to numerous confounding variables. Normal volunteer models use standardised painful stimuli with resulting reduced phenotype variability. Current studies suggest an association between genetic variability and pain sensitivity.

Methods: Data from 50 healthy volunteers in three studies of multi-modal, multi-tissue experimental pain stimulation were included. Skin heat, muscle cuff pressure and visceral pressure were analysed. Genetic variants in the genes coding for the mu, delta and kappa opioid receptors (OPRM, OPRD and OPRK) were studied using multivariate regression models use standardised painful stimuli with resulting reduced phenotype variability. Current studies suggest an association between genetic variability and pain sensitivity.

Results: Reproducibility of baseline data for skin heat, muscle cuff pressure and visceral pressure between studies was confirmed (Cronbach α >0.8). Gender differences in pain sensitivity were seen. Females were more sensitive to skin heat and muscle pressure (p=0.006 and 0.02 respectively). Genetic associations were also found. OPRK was associated with both skin heat pain (p=0.009) and muscle cuff pain (p=0.003). Visceral pressure pain was not associated with either gender or genotype.

Conclusion: Genetic variations in the kappa opioid receptor appear to mediate different pain modalities. Gender remains an independent predictor of pain sensitivity.

Abstract number: P16
Abstract type: Poster

Prevalence of Pain in Outpatients with Cancer

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Introduction: The cancer clinic at our hospital have had an integrative approach with palliative and curative patients since 1993. The knowledge about prevalence of cancer related pain in an oncology outpatient setting is limited and ranging between 40-80%. The aim of this study was to investigate the prevalence of pain in outpatients and to evaluate the correlations with demographic and cancer related variables.

Material and methods: A cross-sectional study among outpatients with histologically verified cancer, age ≥18 years, adequate cognitive function and no surgical procedures last 24 hours were included consecutively during 11 predefined days. The Brief Pain Inventory and the Alberta Breakthrough Pain Assessment Tool were applied as outcomes Furthermore data on demographics, diagnosis, sites of metastasis, treatment and comorbidity were collected. Descriptive, univariate and multivariate analysis were applied.

Results: 305 patients with a mean age of 60 years were included with 93% in WHO performance status of 0-1 and 59% received oncological treatment with a curative intent. The mean score for worst pain last 24 hours, average pain and current pain were 1.96, 1.84 and 1.08, respectively. 24% reported pain score ≥ 4 as their worst pain last 24 hours. 15% reported breakthrough pain. In a multivariate analyses sex and comorbidity was significantly associated with mean average pain. Additionally, comorbidity was significantly associated with mean strongest pain last 24 hours and sex with mean current pain on multivariate analyses.

Conclusion: Our data indicates a lower level of pain compared to earlier studies. This observation may reflect a positive effect of an integrative approach of palliative care into oncology practice. Pain was significantly associated with sex and comorbidity.

Abstract number: P17
Abstract type: Poster

The Use of Cordotomy in Mesothelioma-related Pain: A Systematic Literature Review

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Aims: To synthesise the current evidence on the use of cordotomy in mesothelioma-related pain, with specific reference to safety and effectiveness. This review forms part of a wider study on the use of cordotomy in this patient group in the UK (The INPiC pilot project).

Methods: Eleven databases were searched from inception to January 2011. Two reviewers independently undertook
Nasal Fentanyl for Patient Controlled Treatment of Pain in Cancer

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Background: Slow release opioids are the mainstay for moderate to strong cancer pain. We wanted to challenge this recommendation by giving rapid acting nasal fentanyl formulation on demand as the only opioid for cancer pain. The aim of this pilot study was to determine the feasibility of this approach.

Methods: Adult cancer patients with metastatic disease and pain, that where in need of opioids were included. They received a test dose of nasal fentanyl (NF) before entering a titration phase (1-5 days) followed by a treatment phase (10 days). They were observed 7 days after switching to SR morphine. Pain relief, nausea, sedation, nasal and pharyngeal irritation where assessed on an 11-point numerical rating scale (NRS). Other adverse events were noted by the patient in a diary. Investigator had daily telephone contact with the patients.

Results: Ten patients were included. All underwent the titration phase. Six patients completed the treatment-phase. A total of 226 sprays were taken during the treatment-phase; range 0-6 sprays a day for each patient. Eight of 10 patients had adequate pain relief (decrease of 2 or more at 15 min (NRS)) in more than 50 % of the attempts, while 5/10 had such relief in 80% of the attempts. Three serious adverse events (SAE) were reported as the actual events resulted in hospitalization. These were dizziness, cancer treatment complication and progression of disease. One patient experienced hearing abnormalities. This symptom disappeared when NF was discontinued (possible adverse drug reaction). Remaining adverse events reported such as dizziness, sedation, nausea, nose and pharyngeal irritation were minor.

Conclusion: This explorative study showed that treating pain in cancer patients using NF on demand was feasible, apparently safe and patients experienced significant pain relief. The observed balance between effect and adverse events indicate that the concept should be studied further.

Abstract number: P18
Abstract type: Poster

Use of Calcium and Magnesium to Prevent Oxaliplatin Related Neurotoxicity

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Aim: Sensory neurotoxicity is a dose limiting side effect of oxaliplatin. The postulated cause is interference with ionic channels. Calcium and magnesium pre and post oxaliplatin infusion have been suggested to prevent this.

Methods: We performed a review of all patients who were treated with oxaliplatin over a 2 year period. 25 patients received oxaliplatin with calcium gluconate 1g and magnesium sulphate 1g (Ca/Mg group) and 33 did not (no Ca/Mg group). 49 (84%) patients received oxaliplatin as part of the FOLFOX regimen. Other regimens included XELOX, EOX and FLOX. Peripheral neuropathy was defined and graded by the Common Terminology Criteria for Adverse Events v3.0 and was assessed by a clinical nurse specialist (CG).

Results: 55 (95%) patients had peripheral neuropathy. There was no significant difference in overall neuropathy and the grade of neuropathy between the Ca/Mg group
and no Ca/Mg group. 4 patients required discontinuation of oxaliplatin. One patient (Ca/Mg group) required dose reduction. Patients requiring medical treatment were treated with pregabalin.

<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>No Ca/Mg group</th>
<th>Ca/Mg group</th>
<th>P value (Fisher’s exact)</th>
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</thead>
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<tr>
<td><strong>Neuropathy</strong></td>
<td></td>
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<tr>
<td>Grade I</td>
<td>15/58 (26%)</td>
<td>11/33 (33%)</td>
<td>4/25 (16%)</td>
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<tr>
<td>Grade II</td>
<td>38/58 (66%)</td>
<td>20/33 (61%)</td>
<td>18/25 (72%)</td>
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<tr>
<td>Grade III</td>
<td>5/58 (9%)</td>
<td>2/33 (6%)</td>
<td>3/25 (12%)</td>
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<tr>
<td><strong>Medical treatment</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Dose reduction/discontinuation</td>
<td>5/55 (9%)</td>
<td>2/33 (6%)</td>
<td>3/24 (12.5%)</td>
<td>0.6434</td>
</tr>
</tbody>
</table>

**Conclusion:** Oxaliplatin-induced neuropathy is a drug limiting adverse effect. We found that the addition of calcium gluconate and magnesium sulphate did not reduce the incidence or severity of peripheral neuropathy experienced in our cohort. Oxaliplatin induced peripheral neuropathy may not be reversible. This emphasizes the importance of managing this difficult symptom appropriately.


**Abstract number:** P20
**Abstract type:** Poster

**Effects of High Dose Vitamin C Administration on Fatigue in Terminal Cancer Patients**

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**Aims:** Fatigue is reported by more than 50-70% of patients with advanced cancer as one of their most frequent symptoms. Quality of life in terminal cancer patients is deleteriously affected by fatigue. It was recently reported that improvement of health-related quality of life in terminal cancer patients was demonstrated after administration of high dose of vitamin C. A basic research have shown that proinflamatory cytokines, such as interleukin-6(IL-6) can signal the central nervous system to induce sickness behavior including fatigue. We hypothesized that reduced level of IL-6 might be found after administration of high dose of vitamin C. As the result improvement of cancer fatigue might occure in terminally ill cancer patients. In the present study, we investigated association between plasma IL-6 levels and fatigue in terminally ill cancer patients after administration of high dose of vitamin C.

**Methods:** All patients were given an intravenous administration of 20g vitamin C every other day for two weeks. And then subjects' fatigue was assessed using the cancer fatigue scale(CFS). Blood collection was performed on the same day as the interview was conducted and the questionnaires of CFS were administered. The CFS is a 15-item self-rating scale, which consists of multiple dimensions of fatigue, such as physical, affective, and cognitive subscales. The reliability and validity of this scale have been established by a previous study. Plasma IL-6 levels were measured with an ELISA kit according to the manufacturer’s instructions.

**Results:** Plasma IL-6 levels were significantly reduced after intravenous administration of 20g vitamin C. Decreasing levels of IL-6 significantly correlated with the improvement of CFS, especially with the physical subscale score, but not with other subscale scores.

**Conclusion:** The results of the present study might provide information to develop a new treatment strategy for cancer fatigue in terminally ill cancer patients.

**Abstract number:** P21
**Abstract type:** Poster

**Permanent Vascular Access Device Placement in Palliative Care**

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Permanent vascular access device placement is a timely issue in the field of palliative care. In some cases of long-term therapies, the peripheral venous system can be extensively burdened. Parental administration of intravenous drugs or fluids can be effectively utilized in palliative care, in addition to its function in cancer therapies. We present an overview of risk factors in relation to parenteral application of medicaments as well as a comparison of different types of venous access devices in palliative care. We also offer recommendations about general indications for permanent venous access devices. We describe the most up-to-date methodologies for identifying the most appropriate venous access device for the oncology patient. We present our experience with PICC (peripherally implanted central catheters) implantations used in oncology patients in our centre. PICC’s offer an additional facility for permanent venous access next to venous ports, with low rates of complications. Evidenced-based recommendations for one particular permanent venous access device (PICC or port) versus another overlap, but we do include suggestions based on our own clinical experience in our presentation.
Challenging of the Definition of Constipation in Palliative Care Patients

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Background: Constipation is defined as decreased frequency of complete spontaneous bowel movements (CSBM) to less than 3 per week or subjective patient’s complaints, such as difficulty in defecation, hard stools, straining or incomplete bowel movements (Polish Society of Palliative Medicine Guidelines 2009). Many times frequency of CSBM is the only measure available in palliative care patients.

Aims: To verify the objective measure of the definition by challenging questions:

Is the frequency of CSBM less than 3 per week an accurate criterion for diagnosing constipation in palliative patients?

At what frequency of CSBM the subjective symptoms increase over acceptable intensity level?

Study design and methods: A multicenter questionnaire cohort survey performed in home and hospice patients. Data on frequency of CSBM, Bowel Function Index and subjective assessment of difficulty of defecation (SADD) [NRS 0-10] collected.

Spearman’s rank correlation coefficient used for assessment of the relationship between subjective symptoms and frequency of CSBM. The differences of mean values between the groups were assessed with Chi-squared test.

Results: 265 questionnaires were eligible for analysis. Significant negative correlation was revealed between SADD and frequency of CSBM (corr. coeff. -0.67; p<0.05). SADD was 1.9 (95% CI: 1.4-2.4) when frequency of CSBM was 4 and more per week. It increased to 3.4 (95% CI: 2.6-4.2) when frequency of CSBM was 3 per week, and indicates mild constipation symptoms. Significant increase of SADD appeared if frequency was less than 3 per week or if the time from the last CSBM overcame 2 days.

Conclusions: The definition of constipation in palliative care patients is inadequate as mild subjective symptoms of constipation appear already when frequency of CSBM is less than 4 per week.

Secondary prophylaxis of constipation should aim achieving effective bowel movements at least every second day.

Funded by the authors.

A Clinical Study on the Influence of Hydration Volume toward the Symptoms in Terminally Ill Cancer Patients with Abdominal Malignancies

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Aims: Current discrepancies in the practice of artificial hydration therapy for terminally ill cancer patients have the potential to cause serious clinical problems. The aim of this study is to explore the influence of hydration volume toward the symptoms during the last 3 weeks of life in these patients.

Methods: This was a prospective, observational study of 75 consecutive terminally ill patients with abdominal malignancies during the last 4 years. Primary responsible physicians evaluated the severity of membranous dehydration (calculated based on 3 physical findings), peripheral edema (calculated based on 7 physical findings), ascites and pleural effusion (rated as physiologically ‘undetectable’ to ‘symptomatic’), bronchial secretion, delirium (evaluated by MDAS). A chi-square test was used for statistical analysis.

This study was approved by the IRB of the hospital.

Results: Patients were classified into two groups; the hydration group (n=32; H group) who received 1,000mL or more of artificial hydration per a day, both 1 and 3 weeks before death, and the non-hydration group (n=43; NH group).

The percentages of patients with deterioration in dehydration score in the last 3 weeks were significantly higher in the NH group than in the H group (35% versus 13%; p=0.027), while the percentages of patients whose symptom scores for edema, ascites and bronchial secretion were significantly higher in the H group than in the NH group (57% versus 33%, p=0.040; 34% versus 14%, p=0.037; 41% versus 19%, p=0.036; respectively). There were no significant differences in the degree of pleural effusion and delirium.

Conclusions: Artificial hydration therapy could alleviate membranous dehydration signs in terminally ill cancer patients, but could worsen peripheral edema, ascites and bronchial secretion.

It suggested that the potential benefits of artificial hydration therapy should be balanced with the risk of worsening fluid retention symptoms.

Breathlessness in the Context of Advanced Illness: A Comparison between COPD and Lung Cancer Patients

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Objectives: Patients’ experience of breathlessness at the end of life may vary across different diseases and through the illness course. These differences also may indicate distinct responses by professionals in different stages of the disease and contexts of the individual patient. Therefore the objective of this study was to explore the experience and meaning of breathlessness of patients with COPD or lung cancer at the end of life.

Methods: The qualitative study was embedded in a longitudinal study. Topic-guided in-depth interviews with a purposive sample of patients suffering from breathlessness affecting their daily activities due to advanced (primary or secondary) lung cancer or COPD stage III/IV were conducted. The tape-recorded interviews were transcribed verbatim and analysed using Framework Analysis. Interviews took place either at home or in the hospital.

Results: Ten COPD and eight lung cancer patients were interviewed. Participants reported many similarities in their experience such as the breathlessness due to exertion throughout the illness course, losses in their daily activities, and the experience of breathlessness leading to crises. The main difference was the way how patients adapted to their particular illness experience and the resulting crises over time. While COPD patients more likely gained control over their life with breathlessness, the participating lung cancer patients often expressed a need for security and wanted to say goodbye, facing the possibility of death.

Conclusion: Breathlessness in advanced disease is experienced in a similar way by patients but also leads to distinct reactions and coping mechanisms which are more related to the type and stage of disease than the symptom alone. Professional need to consider this when caring for these patients. The occurrence of breathlessness might provide the opportunity to start a dialog about the illness experience and the organisation of care amongst patients and professional carers.

Abstract number: P25
Abstract type: Poster

Psychological Distress in Cancer and Non-cancer Patients Attending a Palliative Care Unit

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Research aims: There are studies that argue that cancer patients experience increased anxiety and others that postulate that chronic patients experience more anxiety. The aims of the study, were investigate the sociodemographic and clinical differences, as well as the presence of anxiety in both cancer and non-cancer chronic patients.

Method: A total of 175 patients from a pain relief and palliative care unit participated in the study. Patients’ sociodemographic and clinical characteristics were recorded. Also, participants completed the Greek version of the Spielberger State-Trait Anxiety inventory and the Greek version of the General Perceived Self Efficacy Scale.

Results: No statistically significant differences were found between the two patient populations in the measurement of self-efficacy. The only statistically significant differences found between cancer and non-cancer patients were in gender (p<0.0005), marital status (p=0.001), opioids (p<0.0005), and NSAID medication (p=0.002). There were statistically significant differences between the patient populations in the scales of “emotionality” (p<0.0005), “self-deprecation” (p<0.0005) in the Greek version of STAI, and both “trait” (p<0.0005) and “state” (p<0.0005) scales of the original structure.

Conclusions: Non-cancer patients experienced increased anxiety compared with the cancer patient population.

Abstract number: P26
Abstract type: Poster

Demographic Predictors of Symptom Prevalence in Advanced Cancer

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Objectives: Knowledge of the demographic predictors with the strongest impact on symptom prevalence can facilitate symptom management. We aimed to identify the dominant predictor of symptoms from age, gender, performance status (PS), and primary site in advanced cancer.

Methods: Recursive Partitioning Analysis (RPA) identified the dominant predictors of 38 symptoms in 948 consecutive patients. RPA split data into 2 categories. It assessed all possible data splits for the 4 variables and selected the one that maximized the prevalence difference between the 2 categories.

Results: Median age was 65 (range 12-94 years); 55% were male; 65% had ECOG PS 3-4. Most common cancers: lung, genitourinary, gastrointestinal. Gender was not a dominant predictor for any symptom. Age was the dominant predictor
for sleep problems, depression, nausea, anxiety, vomiting, headache, tremors, and blackouts. Symptom prevalence declined with age. PS was the dominant predictor for pain, fatigue, weakness, anorexia, lack of energy, constipation, early satiety, taste changes, confusion, memory problems, sedation, hiccough, hallucinations, and mucositis. Various cancer primary sites were the dominant predictor for dry mouth, dyspnea, weight loss, cough, edema, hoarseness, dizziness, dyspepsia, dysphagia, belching, bloating, wheezing, itching, diarrhea. Head&neck and pancreas cancers individually were both dominant predictors for dysphagia and belching, respectively. Only 2 symptoms (aches/pains, dreams) had no dominant predictor.

Conclusions: 36 symptoms had a dominant demographic predictor. Age was the dominant predictor for 8; the influence was unidirectional. Gender did not predict any symptom. PS was the dominant predictor for 14 symptoms; the influence was bidirectional. Head&neck and pancreas cancers had clinically and statistically significant influence over symptom prevalence. Symptom profiles based on dominant demographic predictors may be present in advanced cancer.

Abstract number: P28
Abstract type: Poster

The Relationship between Symptom Prevalence and Severity and Cancer Primary Site in 796 Patients with Advanced Cancer

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Objectives: Knowledge of differences in symptom prevalence and severity between cancer primary sites may help understand symptom pathophysiology. We examined the relationship between cancer primary sites, symptom prevalence & severity.

Methods: We retrospectively analyzed 38 symptoms in 796 consecutive advanced cancer patients. Because of small patient numbers for certain primary sites, we empirically formed 12 primary site groups (PSGs). Symptom prevalence & severity (mild, moderate, severe) were compared among 12 PSGs using Chi-square test. Pairwise comparisons were done to determine which sites differed. A p-value of < 0.05 indicated statistically significant differences between at least 2 of the 12 PSGs.

Results: Pain, fatigue, weakness, lack of energy & anorexia had the highest overall prevalence & did not differ among PSGs. The 3 most common neuropsychological symptoms (insomnia, depression, anxiety) did not vary among PSGs. 19 of the 38 symptoms (50%) varied significantly between PSGs, in either prevalence, severity, or both. 17 (45% of total) symptoms (belching, bloating, confusion, cough, dyspnea, diarrhea, dyspepsia, dysphagia, early satiety, edema, hiccough, nausea, pruritus, sedation, weight loss, wheezing, vomiting) differed in prevalence. 14 (bloating, cough, dyspnea, dyspepsia, dysphagia, early satiety, edema, headache, hoarseness, nausea, pruritus, sedation, weight loss, vomiting) of the 19 symptoms differed by severity. 12 of these varied by PSG in both prevalence & severity, half were gastrointestinal symptoms.

Abstract number: P29
Abstract type: Poster

Cancer Symptom Clusters: Clinical and Research Methodology

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Objectives: Patients with cancer experience multiple symptoms that frequently appear in groups or clusters. We conducted a comprehensive clinical review of cancer symptom cluster studies to identify common symptom clusters (SC), explore their clinical relevance, and examine their research importance.

Methods: Published studies and review articles on cancer SC were obtained through a literature search. We identified 65 reports. These varied in assessment instruments, outcomes, design, population characteristics, and study methods.

Results: Two main approaches to symptom cluster identification were found: clinical and statistical. Clinically determined SC were based upon observations of symptom co-occurrence, associations, or interrelations. These included fatigue-pain, fatigue-insomnia, fatigue-insomnia-pain, depression-fatigue, and depression-pain. They were analyzed by multivariate analysis. They had low to moderate statistical correlations. Disease- or treatment related SC were influenced by primary cancer site, disease stage, or antitumor treatment. SC determined by statistical analysis were identified by factor and cluster analysis.
Taste Changes amongst Hospice Patients with Advanced Cancer

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Objectives: Alterations in taste sensation may cause poor dietary intake and malnutrition. Identification of taste abnormalities can also help better understand eating difficulties. We evaluated hospice inpatients with advanced cancer about subjective changes in their appetite, taste sensation, and food preferences. We also assessed the influence of taste changes on dietary intake. This was accompanied by objective taste evaluation using standard chemical tests.

Methods: We recruited 15 consecutive hospice inpatients. On day 1, patients were questioned about subjective taste changes, food preferences, and daily dietary intake using a structured questionnaire. A 27-food item checklist provided food preferences based on the four basic taste senses. On day 2, a forced choice 3-stimulus drop test was performed for objective taste evaluation.

Results: There were 7 males, 8 females; median age 68 years (range 49-84). The majority had both subjective and objective taste changes. Changes in taste and food preference were common. Most thought all food was tasteless followed by loss of sweet sensation and meat aversion. None had received either radiation or chemotherapy recently. About half of the participants exhibited anorexia and weight loss with decreased energy intake. Both detection and recognition thresholds for these basic tastes were abnormal for the majority of participants. Reduced sensitivity for sweet and salt taste and altered perception for sour predominated in formal taste testing.

Conclusions: Subjective and objective taste changes in advanced cancer were common. Hypogeusia for sweet and salt, and dysgeusia for sour were predominant. Awareness of individual food preferences helps plan diets with pleasurable meals, overcome anorexia, maintain adequate nutrition, and increase QoL.

Abstract number: P30
Abstract type: Poster

Delirium: Dimension of the Problem in a Palliative Care Service

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Background: Delirium is a potentially distressing complication in patients receiving palliative care. In some studies it seems to be a common symptom however there is a wide-range of incidence and prevalence in such populations.

Aim: To evaluate the occurrence of delirium in patients followed by a palliative care service with inpatient support team and outpatient clinic.

Methods: Prospective longitudinal study conducted from 1st January to 31st March 2011, in a central university teaching hospital. All the inpatients and outpatients admitted to the service during this period were invited to participate and were evaluated with Confusion Assessment Method and Mini-Mental State Examination (inpatients every three days; outpatients in all ambulatory consultations, with intervals longer than three days).

Results: Of the 119 patients evaluated (114 cancer patients) delirium was diagnosed in 49 (41,2%): 11 out of 45 patients evaluated only as outpatients (24,4%); 27 out of 49 patients evaluated only as inpatients (55,1%); 11 out of 25 patients evaluated both as inpatient and outpatient (44,0%) (p<0,05). During the study period 51 patients died and 33 of them (64,7%) were diagnosed delirium whereas only 12 of the 53 patients alive at the end of the study (22,6%) had this diagnosis (p<0.05). The risk of dying was higher in patients with delirium (Odds Ratio 6,26; 95% confidence interval 2,64-14,84). None of the five non cancer patients enrolled in the study (4,2%) was diagnosed with delirium.

Conclusions: In this study, delirium was a common problem in palliative care patients being more frequent in the inpatients setting as well as in the patients who died during the period of the study. Delirium was associated with a higher risk of dying.
Methylphenidate vs. Glicocorticosteroids in Cancer Related Fatigue: A Better Treatment Option? Preliminary Study

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Introduction: Fatigue is one of the most common problems associated with advanced cancer. It is supposed that central-acting drugs, like psychostimulants or widely used glicocorticosteroids can be useful in management of this symptom.

Aim: The aim of this study was to compare the effects of methylphenidate and dexamethason in reducing fatigue in advanced cancer patients.

Methods: Twenty advanced, hospice-care cancer patients participated in the study. The inclusion criteria were: fatigue on NRS ≥ 1, age 18 years or older, Karnofsky performance status 40 or more and no contraindications. Patients were randomized into two arms: 10 patients received 2 mg of dexamethason every day and the other 10 received 18 mg of methylphenidate orally daily. Patients were afforded the same, high level of holistic care (BSC; Best Supportive Care). They were examined with NRS-fatigue, Multidimensional Fatigue Inventory (MFI-20) and the Hospital Anxiety and Depression Scale at the baseline and on day 7, 14 and 28 of the study. On those days decision upon changing the dose of methylphenidate was made accordingly to the clinical effect of the drug.

Results: A tendency towards stronger reduction of the level of cancer related fatigue was observed in the methylphenidate group (with dose ranging from 18 to 36 mg per day) compared to dexamethason group. It is noteworthy that a considerable improvement in depressive symptoms was found in the methylphenidate group. Moreover, in one case, methylphenidate significantly relieved symptoms of painful peripheral polyneuropathy.

Conclusions: Methylphenidate appears to be a beneficial option compared to glicocorticosteroids in management of fatigue in advanced cancer patients. It is important that among our patients the drug was very well tolerated and no serious side-effects were observed. Psychostimulants deserve careful consideration as potential therapeutic agents in such specific patient groups as advanced chronic disorders.

Malignant Spinal Cord Compression (MSCC) and its Implications in End-of-Life Care

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Malignant Spinal cord compression (MSCC) is an unfortunate complication of cancers. The consequences of these conditions include functional activities and impaired mobility. Prompt diagnosis and expedient treatment may help in preventing the sequelae of MSCC.

Aims: To identify complications in patients who have developed spinal cord compression.

Methods: Case services. This is a retrospective chart review of patients referred to a Palliative Care Consult Service from September 2007 - August 2011. Eight patients with an established radiological diagnosis of spinal cord compression were identified.

Results: Prostate cancer was the most common primary malignancy, occurring in 50% of the patients. Other underlying causes were breast cancer, renal cell carcinoma and an unknown primary pelvic adenocarcinoma. All patients received radiation therapy to the vertebrae. Of these, only one individual regained physical and other functional abilities. Pain was reported by all the patients. Reported quality of pain changed following the diagnosis of spinal cord compression. Three patients required opioid rotation; of these 2 were rotated to methadone. Spasticity was also reported by 1 patient. Pressure ulcers which required regular debridements and/or wound vacuum therapy developed in 3 of these patients. Increased burden on caregivers was documented in all the charts leading to admission for palliative and hospice care in 86% of patients. Life expectancy following the diagnosis ranged from 1 - 13 months (average of 4 months).

Conclusion: Spinal cord compression has implications on the physical, emotional, functional and overall wellbeing of patients. The potential for the development of MSCC should be anticipated especially in patients with certain cancers. Treatment should be multidimensional and proactive focusing on the prevention of pressure ulcers. This is imperative as patients appear to have a variable life expectancy following the development of MSCC.

End-of-Life Hospital Transfers in Out-of-Hours General Practice

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Background: During the end of life, many patients experience transfers from home to hospital, and the majority of them die in a hospital.

Aim: To explore the reasons for hospital transfers of palliative care patients in out-of-hours general practices.

Methods: A retrospective descriptive chart study was conducted during a one-year period (1/11/05-1/11/06) in all 8 out-of-hours general practices of the Amsterdam region (Netherlands). Of the 529 charts of palliative care patients, all sociodemographic, medical characteristics and symptoms were recorded. Multivariable logistic regression analysis was performed to identify variables that were associated with hospital transfers at the end of life.

Results: In total, 13% of all palliative care patients for whom an out-of-hours general practitioner (GP) was called were transferred to hospital. Cancer (OR 5.1), cardiovascular problems (OR 8.3), digestive problems (OR 2.5), and endocrine, metabolic and nutritional (EMN) problems (OR 2.5) were significantly associated with hospital transfer for patients for whom an out-of-hours GP was called. Receiving professional nursing care (OR 0.2) and information transfer of the patients own GP to the out-of-hours GP (OR 0.4) were significantly associated with staying at home. Most frequent reasons for hospital transfer as noted by the out-of-hours GP were digestive (30%), EMN (19%), and respiratory problems (17%). The most common digestive problem was vomiting (16%) and the most noted problem for EMN was dehydration (16%).

Conclusion: In order to anticipate potentially undesirable hospital transfers in out-of-hours general practices, GPs should be alert to digestive, EMN, respiratory and cardiovascular symptoms in palliative care patients.

Abstract number: P35
Abstract type: Poster

Emotional Contribution in Patients with Poorly Responsive Pain: A Pilot Study

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Aim: To identify personality traits and psychopathological disorders presents in patients suffering form advanced cancer and difficult pain with emotional distress.

Patients and method: Observational descriptive pilot study by individual psychological interviews.

Inclusion criteria: cancer inpatients receiving Palliative Care in 2009 and 2010. Edmonton Staging System grade III; Emotional distress; Psychological assessment.


Results: 63 patients included. X age: 58 (29-79). Male: 62%. Tumours: Lung 26%; Upper Digestive tract: 23%; Mean Emotional distress by VAS = 6.9 (0-10). More common diagnostics in Axis I-Clinical disorders and other conditions that may be a focus of clinical attention diagnosis were: Pain disorder associated with psychological factors and a general medical condition 90%; Psychological Factors Affecting Medical Condition 89% and Sleep disorder due to insomnia 75%. In Axis II-Personality Disorders and Mental Retardation: Narcissistic personality disorder 22% and in Axis IV-Psychosocial and environmental problems: Phase of life problem 49%; Relational problem related to a mental disorder or general medical condition 41%. We could identify a mean of 6.9 personality traits and psychopathy per patient. Most frequent were: regressive traits 53%; immaturity 56%; victimizing behavior 81%; low tolerance to frustration 77%; impulsivity 67%; alexithymia 89%; controlling behavior 98% low insight 63%; tendency to denial and dissociation 89%; history of drug addiction 21%; history of psychopathology 5%.

Conclusions: Components of emotional distress in advanced cancer patients suffering from poor prognosis pain were: disorder associated with general medical condition and pain; controlling behaviour, alexithymia, tendency to denial-dissociation and victimizing behaviour. These results will assist the planning of psychological support.

Abstract number: P36
Abstract type: Poster

The Validation and Feasibility of Using a Palliative Care Modified Richmond Agitation-Sedation Scale (RASS-PAL) Instrument in a Palliative Care Inpatient Unit: A Pilot Study

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Background: The EAPC recommended framework for palliative sedation (PS) proposes the Richmond Agitation-Sedation Scale (RASS) or similar tool to assess distress in palliative care (PC) patients with lowered consciousness. The RASS, developed and validated in intensive care, guides therapy for both sedated and agitated patients but has not been validated for use in the PC setting. We recently tested a modified version (M-RASS) and demonstrated good inter-rater reliability. Results suggested that further modification was required for PC inpatients and the RASS-PAL reflects this.
**Aims:** We conducted a mixed methods prospective study to validate the RASS-PAL instrument in PC inpatients.

**Methods:** Health care professionals (HCPs) assessed patients (receiving PS or with agitated delirium) at hourly intervals on Day 1 (T1-T4) and 24 hours later (T5). At each time point, 2-3 HCPs were to assess the same patient simultaneously but independently. HCPs also completed a short survey and semi-structured interview.

**Results:** Five PC physicians, 8 nurses (7 bedside nurses [BSN], 1 Practice Support Nurse [PSN]) participated. There were 35 observations for 9 patients with 2-3 HCPs present, and 13 surveys and 13 interviews. The intraclass correlation coefficient range for T1-T5 was 0.84 to 0.98. Surveyed HCPs agreed that the tool measured sedation well and was easy to use. Qualitative data from transcribed interviews was codified with emerging themes identified by the research team on a consensus basis. Themes included strengths and limitations of the tool in the PC setting, standardization of HCP practice, interprofessional communication and a need for formal education before integration into clinical practice. Comparative data between the M-RASS and RASS-PAL will also be presented.

**Conclusion:** The RASS-PAL has the potential to standardize PS practice and improve patient care. For PC settings, education appears to be important to ensure its appropriate application.

(No funding source)

**Abstract number:** P37

**Abstract type:** Poster

**Defining the Palliative Patient. A Systematic Review. (Whole Article Is Submitted for Publication in Palliative Medicine as Revised Manuscript)**

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**Background:** The lack of a clear definition of the palliative patient limits the comparison of results across different studies and impedes implementation of research findings in everyday practice.

**Aim:** To propose minimum data that could be integrated in the definition of a palliative patient.

**Design:** Review of medical literature assuming that peer-reviewed randomized controlled trials (RCTs) in palliative care research have clear descriptions of their palliative patient. We systematically described relevant characteristics of the study populations of 60 eligible RCTs.

**Data sources:** MEDLINE, EMBASE, CINAHL, and PSYCHINFO including all non-cancer RCTs (1 January 1995 - 4 March 2010) and an equivalent number of the most recent cancer RCTs (1 January 2003 - 4 March 2010).

**Results:** Half of the non-cancer studies were excluded because they did not relate to palliative care. The authors conclude that peer-reviewed RCTs have no clear definitions of their palliative patients and illustrate the diversity of this patient, the lack of consensus concerning the attributes of palliative illnesses and the ambiguous use of the adjective ‘palliative’.

**Conclusions:** We propose elements of patients’ health status (e.g. an incurable, progressive, life-threatening disease with no possibility of obtaining remission or stabilization or restraining the illness) and the care delivered to them (e.g. a holistic interdisciplinary approach that focuses supporting the quality of the end-of-life) to be included in the definition of a palliative patient. We also suggest considering patients’ readiness and a vision of palliative care shared by the patient and all caregivers involved as potentially important elements in this definition.

**Abstract number:** P38

**Abstract type:** Poster

**Assessing the Correlates and Predictors of Clinician-rated Psychological Distress in a Cancer Pain Classification System**

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**Aims:** Psychological distress (PD), in the context of the pain experience, has been identified as a significant feature of a pain classification system. The aim of this study was to explore the relationship between clinician-rated PD (CR-PD) and patient-reported PD (anxiety, depression, well-being) and pain in an advanced cancer population. We hypothesized that CR-PD would be significantly associated with patients’ self-reports of anxiety, depression, well-being and pain.

**Methods:** This study is an extension of a multicentre pain intensity study. A total of 402 patients were recruited from 6 specialist palliative care sites (inpatient and outpatient palliative consult services, tertiary palliative care units, hospice settings). On initial assessment, a palliative care specialist asked patients to rate their current pain intensity, anxiety, depression and well-being on 11-point (0-none to 10-worst) numerical rating scales. The Edmonton Classification System for Cancer Pain, which includes CR-PD, and patient demographics were also recorded.
**Results:** 373/402 (93%) patients had a cancer pain syndrome: mean age 63 (SD 14); females 52%; median pain intensity 5. 89/373 patients (24%) had CR-PD. Patients with CR-PD had significantly higher mean scores for anxiety (p< .0001), depression (p< .0001), well-being (p=.0007) and pain (p=.0326), than those without CR-PD. In the univariate logistic regression model, depression (p< .0001), anxiety (p< .0001), well-being (p=.0036) and pain (p=.0153) were significant predictors of CR-PD; while only depression (p< .0001) and pain (p=.0527) were significant predictors in the multivariate stepwise model (0.10 entry level).

**Conclusion:** Self-reported depression and pain intensity may be better predictors of patients who express their psychological distress through their pain than anxiety or well-being. Future research needs to be conducted to identify other objective measures for assessing psychological distress within the pain experience.

**Abstract number:** P39

**Abstract type:** Poster

**Both Physician Based and Patient Based Quality of Life Scores Predict Survival in Patients with Painful Bone Metastases: Results from a Randomized Radiotherapy Trial**

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**Aims:** To study if physician and patient based evaluation of quality of life (QOL) predicts survival.

**Methods:** In the Dutch Bone Metastasis Study, 1157 patients with bone metastases were randomized between two radiotherapy schedules. During follow-up, 74% died. At randomization, patients listed their well being on a 100mm visual analogue scale (VAS) and a 7-point verbal rating scale (VRS). The treating physician noted the performance using the Karnofsky Performance Score (KPS). Per scale, patients were grouped into three cohorts (high, intermediate, or low quality of life). The Kaplan Meier method was used for survival analyses. A Cox proportional hazards model was used for univariate (UV) and multivariate (MV) analyses. For correlation, Pearson's coefficients were calculated.

**Results:** The VAS, VRS and KPS were listed in 91%, 93% and 99% of patients, resp. All scores were positively associated, with higher KPS resulting in higher VAS and VRS. All scores significantly predicted survival (UV, p< 0.001) (Table 1). In the MV analysis, only KPS remained highly significant (p< 0.001). Since VAS and VRS measured equivalent QOL items (r= 0.6, p< 0.001), combining both scores was not predictive anymore (MV, for VAS, p= 0.09, VRS, p= 0.13).

**Conclusions:** Both physician based KPS and patient based VAS and VRS predicted survival. In the MV analysis, only KPS remained highly significant. For future studies, a physician based quality of life score can aid clinical decision making in palliative patients.

**Abstract number:** P40

**Abstract type:** Poster

Identification of Patients in the Last Year of Life in the Acute Hospital Setting: Evaluation of the Use of Modified Gold Standards Framework Prognostic Criteria

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The End of Life (EoL) Care Strategy for England requires hospitals to identify patients in last year of life and to discuss their treatment preferences. Identifying people in last year of life remains difficult. Gold Standard Framework (GSF) provides a prognosis prediction tool. However, it contains some subjective criteria, which may not be reproducible. It was estimated that about 18% of beds are occupied by those in last year of life at our district general hospital.
Aims: To assess the feasibility of using a modified Gold Standard Framework (mGSF) prognostic tool to identify patients in the last year of life in acute hospital.

Methods: The mGSF prognostic criteria were modified by removing subjective criteria. The modified tool contained objective prognostic criteria for cancer, COPD, heart and renal failure, dementia, stroke, motor neurone disease and a separate category of “do not resuscitate order”. Patients in all 240 acute medical beds were screened against the mGSF on four consecutive Wednesdays. Time taken to complete the mGSF was recorded for each patient. Information on patient deaths was gathered from the hospital database four months after the screening.

Results: Of 960 patients screened, the mGSF identified 124 (13% of medical inpatients) to be in the last year of life. The main disease categories were advanced cancer (30%) and COPD (27%). The mean mGSF completion time was 1.9 minutes. Four months later, 54% of the patients identified had died. Using the figure of 18% as the accurate estimate of prevalence the mGSF identified 66% of all acute medical patients who would be in last year of life. The apparent shortfall could be explained by the removal of disease-specific subjective criteria.

Conclusion: The mGSF tool identified most of cancer and non-cancer patients in last year of life of whom more than half died in less than four months, without significant impact on time in a busy clinical setting of an acute district general hospital.

Abstract number: P41
Abstract type: Poster

Family Satisfaction with the Tertiary Palliative Care Unit - What Can We Learn from Implementing FAMCARE?

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Aims: Our Tertiary Palliative Care Unit (TPCU) admits patients identified by palliative care consultants as having problematic symptom and psychosocial issues difficult to manage in other care locations. In a recent accreditation review, the TPCU had 1 major weakness - family satisfaction with care was not being formally evaluated. Our national accreditation program has endorsed FAMCARE, a tool designed to measure caregiver satisfaction.

Methods: As of January 2011, the FAMCARE tool has been mailed to the identified closest relative of the patient two months after the patient’s death on the TPCU. Since that time, 99 surveys have been sent out and there have been 30 returned forms at the time of writing.

Results: The FAMCARE tool instructs recipients to think about the care that their family member received and to answer twenty questions as being very satisfied (VS), satisfied (S), undecided (U), dissatisfied (D), or very dissatisfied (VD). With the exception of one item, all other items were rated as S or VS by over 83% of participants. The D or VD replies for each question never exceeded 7%. The questions that received the highest percentage of S or VS responses (93%) were: 1) availability of a hospital bed, 2) availability of nurses to the family, 3) availability of doctors to the family, 4) how thoroughly the doctor assesses the patient’s symptoms, and 5) answers from health professionals.

Conclusion: Despite the high level of symptom and psychosocial distress in patients admitted to the TPCU, the reported level of family satisfaction is gratifying. Refining the FAMCARE questions to capture satisfaction in different locations of our Zone Palliative Care Program would increase the value of this assessment, improve our self-evaluation, and guide program improvement.

Abstract number: P42
Abstract type: Poster

Measuring Avoidable and Inappropriate Hospitalisations at the End of Life - A Research Protocol of the FLIECE-study

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Background: Hospital admissions at the end of life can result in poor quality of death and dying and they have a negative impact on health care expenditures. Although most people prefer to die out-of-hospital, in many countries a majority spend their last days in hospital. However, little is known about the avoidability and appropriateness of such hospitalizations and an instrument to estimate their prevalence is lacking.

This study, as part of the Flanders Study to Improve End-of-Life Care and Evaluation Tools (FLIECE-study), aims to
explore the perspectives of caregivers and relatives on hospitalizations at the end of life, to develop a measurement instrument and a protocol to assess the avoidability and appropriateness of such hospitalizations and to estimate their nationwide prevalence, characteristics and associated factors.

**Methods:** In order to be able to grasp the avoidability and appropriateness of a wide variation of hospitalizations at the end of life, five focus groups will be organized with physicians (1), nurses (1) and family caregivers (according to 3 different disease trajectories of their deceased relative). Their perspectives, combined with the opinions of two expert panels will result in an instrument to measure avoidability and appropriateness of hospitalizations at the end of life. This instrument will be validated using hospital records.

This validated instrument will be used in a survey to estimate the nationwide prevalence of potentially avoidable and inappropriate hospitalizations, their characteristics and associated factors.

**Conclusion:** This part of the FLIECE-study will result in a measurement instrument and a protocol to adequately assess avoidability and appropriateness of hospitalizations at the end of life, that will be useful for caregivers, policy makers and other researchers.

**Abstract number:** P44
**Abstract type:** Poster

**Translation and Cross-cultural Adaptation of the Palliative Performance Scale Version 2 (PPSv2) into Catalan**

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**Introduction:** The PPSv2 measures the functional status of patients receiving palliative care. Outcome measurement has a major role to play in improving quality, efficiency and availability of palliative care.

**Aims:** To translate the PPSv2 into Catalan and to assess its cross-cultural validation.

**Methods:** The process was designed in 2 phases.

**Phase 1:** Translation process was obtained using a reverse translation method by 4 competent health bilingual professionals. Grammar, linguistics and semantics were corrected to detect comprehension problems by 2 experts in Catalan grammar, and reviewed by the researchers to ensure its equivalence with the original text.

Linguistic complexity was measured through statistical readability (Szigrist-Pazos formula). The reverse translation into British and American English was back translated by 2 bilingual English native speakers.

**Phase 2:** The assessment was carried out on 30 consecutive patients admitted in the oncology ward in two different moments (day 0 and 2) by 4 different health professionals (2 nurses and 2 doctors). Inter-observer reliability and intra-observer reliability were calculated with test-retest method. To assess the inter-observer and the test-retest reproducibility, we calculated the intra-class correlation coefficient (ICC). The professionals were trained before the administration of the test.

**Results:**

**Phase 1:** According to the Szigrist formula, the text was legible. After reverse translation, it was needed to clarify the terms between sickness and illness. The result was the securing of the Catalan version of the PPSv2.

**Phase 2:** The Test-retest was measured on days 0 and 2 and an ICC=0.92 (0.76-0.97) was obtained.

**Conclusion:** The Spanish PPSv2 is a valid and reliable tool for measuring the performance status of patients receiving palliative care. Further studies are being carried out to demonstrate Catalan PPSv2 utility in daily clinical practice with a greater number of patients and health professionals.

**Abstract number:** P45
**Abstract type:** Poster

**Fall Prevention in a Palliative Care Unit: The Use of a Bed-exit Alarm in Practice**

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**Introduction:** Patients admitted to a palliative care unit are at risk of falls. The aim of this study was to evaluate a bed-exit alarm during the night and to prevent falls in a 6-room palliative care unit.

**Methods/design:** A stand alone infra-red sensor device (Optiscan®) was placed in each room. If the infra-red field was crossed, an alarm was sent to the digital wireless phone of the nurse who checked the patient as soon as possible to prevent falls. The registration period was between 8 pm and 8 am. Each alarm was automatically recorded in a central database. The nurse scored the alarms as true positive (TP) or false positive (FP) and recorded any falls. An alarm followed by an observation of a patient vacating the bed was considered a TP while no such observation was recorded in the administration of the test.

**Results:** From 9/05/2011 to 3/10/2011, 28 patients were monitored in the palliative care unit of ZNA Middelheim. In total 525 alarms were recorded. 136 alarms (26%) were not attributed mainly during the briefing period of the nurses. From the 389 evaluable alarms, 296 alarms (76%)
were registered as TP and 93 alarms as FP. One fall incident occurred after an alarm during the study.

**Conclusions:** Optiscan® confirmed in 76% of the alarms that a patient was leaving the bed. One fall occurred in the 5-month period using this system. In comparison, 3 falls were reported in a 6-month period before the use of bed-exit alarms.

There was a relatively high rate of false alarms in this study. This could be due to the sensitivity of the device to other stimuli but also to events missed by the nurse.

Nonetheless, the implementation of this system in the setting of a palliative care unit was positively evaluated by the nurses.

**Abstract number:** P46  
**Abstract type:** Poster

**Improving Advance Care Planning in Primary Care: A Research Design for the Development of a Complex Intervention**

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**Background:** Advance care planning (ACP) is a process of communication between the patient, his/her family and health-care providers regarding the patient’s future care for the event of the patient’s incapacity to make decisions. However, ACP discussions rarely occur. In Belgium, GPs play a pivotal role in the (end-of-life) care of patients, placing them in an ideal position to initiate ACP. This study aims

1. To develop an intervention aimed at improving ACP in primary care and
2. To evaluate this intervention in a pilot study.

The broad definition of ACP requires an intervention that is targeted at both patients and their GPs, making this a complex intervention.

**Method:** Firstly, a systematic review about the effectiveness of existing interventions aimed at starting up ACP in primary care will be conducted. A second systematic review will examine the barriers and facilitators for GPs to implement ACP in daily practice. The results of the reviews will be discussed in focus groups with Flemish GPs in order to integrate their perceptions in the development of the intervention. In a next phase, the intervention will be developed. The intervention aimed at patients will be presented to patients with advanced cancer during in-depth interviews to adapt the intervention to their needs. Finally, the intervention will be evaluated in a pilot study. GPs and patients will be randomized to an intervention group (respectively the GP-intervention and the patient-intervention) and a control group (usual care). Measurements by GP and patient questionnaires will take place at t0 before the intervention, at t1 two months after the intervention and t2 twelve months later.

**Discussion:** This study is an intensive process aimed at distilling the best intervention to promote ACP in the GP-setting from all existing evidence and research. This study takes not only the perceptions of GPs in account, but also includes the experiences and needs of patients, which is a major ethical challenge.

**Abstract number:** P47  
**Abstract type:** Poster

**Gait Assessment: A Potential Objective Surrogate Clinical Biomarker of Pain and Response to Interventions**

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**Background:** Cancer pain assessment can be challenging as it is subjective and influenced by factors such as mood and catastrophizing. In the absence of objective pain measures, a surrogate marker such as the impact on physical functioning would aid pain intervention assessment. The GAITRite® walkway system measures gait and may provide a novel objective surrogate clinical biomarker of pain, especially when it affects the way people walk.

**Aims:** To explore the relationship between objective measures of gait and subjective measures of pain, mood and catastrophizing.

**Methods:** A secondary data analysis of 93 patients with cancer induced bone pain (n=51) and cancer treatment related neuropathic pain (scars and peripheral neuropathy n=42) in two pain intervention trials. Assessment at baseline and 4-8 weeks after commencing treatment included: GAITRite® (a 4.2 metre walkway with embedded computer connected sensors that measure gait velocity [cm/s] and cadence [steps/min]), Brief Pain Inventory (BPI), Hospital Anxiety and Depression Scale and Pain Catastrophizing Scale. Responders were defined as having ≥30% total BPI
Background: Preserving dignity can be considered as a goal of palliative care. To provide dignity-conserving care, it is relevant to identify the factors that influence a patient’s self-perceived dignity. This study aims to develop an instrument to measure factors affecting self-perceived dignity that has good content validity and is appropriate for use in practice. 

Methods: Data were collected in the Advance Directives Cohort Study. In 2008, the cohort received a questionnaire with 31 items that might influence one’s self-perceived dignity. For a subsample of people with poor health (n=292), we analyzed which items could be removed because of the mean scores for presence of the item and its influence on dignity.

Results: The 31 items fell into four domains: evaluation of self in relation to others, functional status, mental state, and care and situational aspects. Mean scores for presence and influence on dignity showed large differences and were not correlated. Six items were scarcely present and did not substantially affect self-perceived dignity. Because three of these were expected to influence dignity in other settings, only three items could be removed and two items could be combined into one. After calculating correlations between conceptually similar items, one extra item could be removed.

Conclusion: Reducing the instrument to 26 items and dichotomizing the answer option for presence increases its feasibility for use in practice. The instrument offers an important step to better understanding the phenomenon of self-perceived dignity by gaining information directly from patients.

Main source of funding: Pieter van Foreest stichting, NVVE (Right to die-NL) and NPV (Dutch Patient Association).

Abstract number: P49
Abstract type: Poster

Neuropsychological Measurement in Cancer Patients: A Validation Study

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Aims: To validate Continuous Reaction Time, Finger Tapping Test, Digit Span Test, Trail Making Test B, and Mini-Mental State Examination in cancer patients in palliative care.

Methods: Brazilian/Danish study in development since Jun 2010. Each country is assessing 2 groups composed by 150 patients and 150 healthy controls. Inclusion criteria: cancer, Karnofsky Index≥40%, age≥18y,≥ 6y schooling, stable medications for 4d. Exclusion criteria: brain tumor/metastases, Hg< 6.0 mmol/l, creatinine>150 mmol/l, K< 3.0 or > 5.2 mmol/l and iCa>1.30mmol/l, hepatic dysfunction, psychiatric diseases, communication/physical impairment, misuse of drugs/alcohol (last alcohol intake≥24h). Exclusion criteria for controls: cancer and diseases interfering with cognition. Reliability analysis: test-retest and internal consistency. Validity analysis: construct, discriminant and concurrent. The preliminary results on Trail Making Test B (TMT B) are presented, which was analyzed with regard to time to conclude the test and number of mistakes.

Results: The Brazilian study has assessed 94 patients (age=53.7y (SD=8.0), schooling=10.0y (SD=4.7), and 39 controls (age=46.9y (SD=15.0), schooling=11.5y (SD=5.3)). TMT B discriminated patients from controls regarding time required to complete the test in the 1st
Abstract: The aim of this study was to assess the accuracy of the Pan Birmingham Cancer Network Risk Assessment Tool (PTP tool) in identifying patients at risk of venous thromboembolism (VTE) in palliative care. Data from a casenote audit in seven hospices in England and Wales showed that the tool identified 77% of patients with a reversible increased VTE risk, but only 16% of whom had symptoms. No reversible increased risk was identified in 23% of whom 16% had symptoms. A sensitivity and specificity is thus 37% and 78% respectively.

Conclusion: Hospice inpatients are at risk of VTE. This tool aims to identify who needs PTP, but despite apparent high specificity, benefit may be limited by low sensitivity. Further work is needed.

the study. The study participants’ individual BIS indexes cover values from minima between 29 and 40 and maxima between 74 and 98 which result in total ranges between 38 and 68 points.

Increasing BIS values give notice of waking up and decreasing BIS values are displayed after sedative or analgesic medication.

Conclusions: The application of BIS monitoring was well tolerated by the participants. Despite rapid up- and downturns and rather individual ranges of BIS values, the BIS index seems to be able to differentiate between phases of sleep and alertness.

Abstract number: P52
Abstract type: Poster

Palliative Care Providers’ Opinions of the Edmonton Symptom Assessment System Revised (ESAS-r) in Clinical Practice

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Aims: The Edmonton Symptom Assessment System (ESAS) is a widely used self-reporting symptom intensity tool for assessing nine common symptoms in palliative care; ratings range from 0 (none, best) to 10 (worst). The ESAS-r is a revision of the ESAS; it provides definitions for potentially confusing items, specifies the timeframe as “now”, and reorders symptoms into physical and psychological, with wellbeing as last item; also, the example of constipation is given for “other symptom”. A multicentre study in palliative care patients showed that the ESAS-r was significantly easier to understand than, and preferred to, the ESAS. The ESAS-r replaced the ESAS throughout our Zone Palliative Care Program (ZPCP) in January 2011. The aim of the study was to obtain palliative care providers’ opinions of the ESAS-r in clinical practice.

Methods: In September 2011, surveys were distributed to 133 ZPCP staff in acute care/cancer care/community consultation services, the tertiary palliative care unit and hospices. The survey included 11 items rated on a 5 point Likert scale (1=strongly disagree, 5=strongly agree), and 5 free text items.

Results: 59/133 (44.3%) surveys have been returned so far (8 physicians, 43 nurses, 8 other/not specified); median years of practice in palliative care is 7.5. Item agreement rates (agree/strongly agree) were: definitions for tiredness 94.7%, drowsiness 87.7%, depression 89.3%, anxiety 80.7%, wellbeing 82.1%; timeframe 77.2%; reordering symptoms 92.7%; wellbeing last 87%; example of constipation 83.9%; adoption for use in clinical practice 94.7%. The most commonly cited strength of the ESAS-r was that it is easier to complete/clearer than the ESAS (n=13). Multiple suggestions for improvement were made, with the most common being a need to clarify the lack of appetite item (n=5).

Conclusion: Palliative care providers’ opinions of the ESAS-r in clinical practice are highly favourable. Further work is needed on definitions, timeframe and terminology.

Abstract number: P53
Abstract type: Poster

The Patient’s Story in a Palliative Care Setting

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Aim: This qualitative project aimed to review the quality of a service by working together, sharing information and making changes. A multi professional palliative care team - involving Occupational Therapists/ Macmillan Nurses and Social worker worked together with patients and carers to share the story of their palliative experience. The project was registered with the Health Board, ‘Patient story framework’, thus gaining ethical approval.

Method: Team members selected certain patients from a designated period to tell their story. Exclusion criteria included terminal stage of illness and recent bereavement. Letters were sent out to explain the process, and patients/carers replied if they were interested in telling their story. Semi structured interviews were arranged by 2 different team members. Transcription of results and themes were identified using a grounded theory approach to identify common themes.

Results:
• 6 out of 13 patients/carers completed interviews. What worked well?
• Speed of response / inclusion of all family
• Staff attitude - support and calm manner
• Anticipation of future needs
• Regular contact
• Advanced levels of knowledge
• Practical and emotional support. What didn’t work well?
• Confusing number of professionals involved
• Slow response to messages
• Failure to acknowledge that death was imminent
• Bad news given badly by wider professional contacts
• Pressure on team - resulting in cancelled appointments
• Inappropriate terminology from generalist staff “casually cruel”

Conclusion: Areas to improve: Communication, Team work, Education of external agencies. The stories highlighted the importance of the support role - not just crisis management.
Recognition of both strengths and weaknesses is a starting point to improve service.

There is a need to implement changes and repeat the process. Overall this is an easy and realistic way of working together as a team, and with patients/careers to improve the quality of your service.

Abstract number: P54
Abstract type: Poster

Evaluation of the Welsh Integrated Care Pathway (ICP) for the Last Days of Life

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Through the implementation of the All Wales Care Pathway for the End of Life, the Welsh Assembly Government aims to ensure good end of life care is universally available across Wales. Ten clinical processes embedded within the pathway are based on evidence where available, or expert consensus.

Implementation of clinical processes was evaluated in a national, retrospective audit of deaths between May 2007 and August 2009. A sample of up to 60 records of recently deceased patients were reviewed from hospital (24), community (20), hospice (5) and specialist inpatient (4) settings. Data extraction using a standard template was carried out by two researchers at all sites to indicate whether these processes had been implemented. A total of 1184 records were retrieved. 202 records were excluded due to sudden death (e.g. cardiac arrest) or incomplete data on place of death, leaving a sample of 982. 580 patients (59%) had received end of life care through the pathway.

Pathway use was associated with implementation of all clinical standards other than for daily review, where implementation was consistently high with (85%) or without the pathway (81%). The mean positive difference in implementation for other standards where the pathway was used was 52% (range 29%-81%). A composite measure of implementation across all processes showed the significant effects of both pathway use $F(1,965) = 464.65, p=0.00$ and care setting type $F(4,965) = 28.83, p=0.00$ on implementation.

These data suggest that use of the pathway is an effective strategy to implement best practice in end of life care. The policy context limits opportunities for the prospective randomised evaluation of implementation. However variation in implementation across sites and the influence of setting type highlights the mediating effect of organisational context which, together with different methods of feedback, may provide a useful agenda for implementation research within end of life care.

Abstract number: P55
Abstract type: Poster

Differences in Quality of Care of Patients with Lung Cancer Compared to COPD and Other Forms of Cancer in the Last Week According to the Swedish Palliative Registry

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Aims: Analysis of a national palliative registry (NPR) showed a difference in the symptoms between patients dying of lung disease and cancer. How do patients with lung cancer compare to patients with COPD and with cancer?

Methods: Data from 2008 was compared to the National Cancer Registry (NCR) to find patients with lung cancer. This group was compared to patients with other cancer and COPD, and analyzed with the $\chi^2$ test.

Results: Of the 8684 patients with a diagnosis of cancer according to the NPR 6882 were also in the NCR, whereof 1181 had lung cancer. 700 patients had COPD.

The NPR contained 8% of all deaths in the nation; 30% of all lung cancer and other cancer/deaths respectively, and 20% of COPD.

There was no difference in care setting between the patients with lung cancer and cancer (majority in advanced palliative care), while the patients with COPD were much more prone to die in hospital or in residential age-care. The patients with lung cancer had significantly more dyspnea, noisy breathing, anxiety or any symptom ($p<0.001$), confusion ($p<0.046$), but significantly less nausea ($p<0.001$), and pain ($p=0.006$) than patients with other forms of cancer. Compared to the patients with COPD they had more pain ($p=0.002$), but less dyspnea ($p<0.001$), any symptom ($p=0.045$) and caregiver’s lack of knowledge of symptoms ($p<0.001$).

Both cancer groups had the same information that they were dying and died alone in the same extent, but the patients with COPD were less informed and died more often alone.

Conclusion: There was a large difference in the number of cancer diagnoses in the NPR and the NCR. The reason for this is unknown and demands investigation.

Patients with lung cancer have more symptoms than other cancers. This may be second to the nature of the disease, nurse’s vigilance but also to sample sizes. Patients with COPD receive less secondary palliative care and therefore less information about their situation.

Funding was from NPR and local research funds.

Abstract number: P56
Abstract type: Poster

Audit of Length of Stay and Discharge Process of Patients Admitted to Velindre Cancer Centre Following a Diagnosis of Metastatic Spinal Cord Compression
Evaluating Outcomes in a Comprehensive Integrated Palliative Care Service

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Aims: Our Zone Palliative Care Program (ZPCP) has a comprehensive integrated service delivery model that provides 24-hour 365 day consultation services to all acute, community and rural locations in the health care zone. In addition, there are 20 beds in a Tertiary Palliative Care Unit (TPCU) and 64 Hospice Palliative Care Unit (HPCU) beds in 4 locations. Standardized assessments are used in all locations to enhance clinical care and administrative reporting of outcomes. Patient data are entered into a program-wide electronic database record. Our aim was to examine demographic and symptom acuity variation across locations of care.

Methods: All 11763 palliative care patients seen by the ZPCP over the last 3 years were included. Anonymized data were retrieved from the electronic database.

Results: Workloads have steadily increased over the last 3 years in all locations, with the most significant growth in HPCU admissions from 586 to 743 patients. Non-cancer patients ranged from 2% in the HPCU to 25% in Acute Care. There were significant variations in cognition and performance status between locations with the lowest scores in HPCUs. Complexity of pain, as measured by neuropathic pain, incident pain and psychological distress, was significantly worse in the TPCU compared to other locations. Pain intensity and other symptom intensity scores were higher in the TPCU compared to most other locations.

Conclusions: The majority of patients seen in our program have a cancer diagnosis, with 2-25% presenting with a non-cancer illness. Variations in symptom acuity between sites provide evidence of appropriate matching between patients and locations of care. Optimal management of patient care and evaluation of outcomes therefore requires routine assessment and collection of symptom assessments and ongoing program evaluation. Meeting the needs of both cancer and non-cancer patient requires appropriate resources and locations of care to match symptom acuity.

Abstract number: P58
Abstract type: Poster

Access to Palliative Care Services - Does it Matter which Hospital You Are in?

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Aims: Our Zone Palliative Care Program (ZPCP) has a comprehensive integrated service delivery model that provides 24-hour 365 day palliative care consultation services to all acute care, community and rural locations in the health care zone. In addition there are 20 beds in the Tertiary Palliative Care Unit (TPCU) at one acute care site. Consultant teams see patients in 4 main acute care sites, while another interdisciplinary team serves the TPCU. The TPCU receives referrals from a large geographic area for the most complex patients who are difficult to manage in other less resourced locations of care. Patient data, including demographics, duration of care, and standardized assessments, are entered into an electronic database. Our aim was to assess the possible impact of the TPCU location on palliative care consultation services received at the 4 acute care sites.
Methods: Eligibility criteria included all palliative care patients admitted to the TPCU; as well as those seen by consultant teams at 2 large acute care hospitals (Sites 1 and 2) and 2 smaller acute care hospitals, one without a TPCU (Site 3) and one with the TPCU (Site 4). Data were extracted from the database over 3 years (06/2008 - 06/2011).

Results: TPCU admissions (by year): 240/235/250. Acute care hospital consults (by year): Site 1: 596/629/638. Site 2: 478/481/531. Site 3: 190/187/171. Site 4: 239/247/251. The distribution of consults over the 3 years by location was: Site 1 (40%), Site 2 (32%), Site 3 (12%), Site 4 (16%).

Conclusions: The proportional distribution of consult volume is influenced by many factors, such as number of hospital beds, maturity of palliative care team, visibility of team members, and differences in population served by hospitals. However, there does not appear to be any evidence that the location of the TPCU is biasing patient access to palliative care services. Our ZPCP continues to provide equitable service provision regardless of location of hospital admission.

Abstract number: P59
Abstract type: Poster

Low Opioids Consumption in Egypt. Root Cause Analysis

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Background and aims: A review of the latest International Narcotics Control Board (INCB) morphine data (2008) reported by governments reveals that low- and middle-income countries (as defined by the World Bank), representing 83 per cent of the world's population, consumed a mere 9 per cent of global medical morphine consumption. High-income countries, accounting for only 17 percent of the global population, consumed nearly 91 per cent of morphine.

In Egypt, the latest (2008) registered morphine consumption is 0.149813 per capita while that of morphine equivalence is 0.1397451 which are very low rates compared to other countries in middle east.

Several barriers to the adequate management of pain have been identified at different level: at the national policy level, in the provision of health care, and among patients themselves. The aim of this analysis is to identify the root of the problem that enables us to do lasting solutions rather than band-aid approaches.

Methods: After organizing a comprehensive multidisciplinary team, meetings of brainstorming were held to identify and categorize all factors of the problem. Then we create a cause-and-effect diagram (FISHBONE). Once the fishbone diagram was completed, the various causes are discussed to determine the root of the problem.

Conclusions: We conclude that under-awareness and under-education of people either in governmental and non-governmental communities is possibly the root cause of this problem. This may have a very negative impact on availability, professional use, legislation and patient’s confidence of these drugs.

Health care professionals need to engage regulators in dialog to eliminate regulatory barriers that govern the prescribing and dispensing of opioids in our country. They also have a professional obligation to assist regulators and law enforcement personnel in identifying persons who may be involved in diverting opioids for nonmedical use.

Abstract number: P60
Abstract type: Poster

An Audit of the Management of Malignant Spinal Cord Compression Compared to National and Local UK Guidelines

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Background: Malignant Spinal Cord Compression (MSCC) is a well recognised oncological emergency affecting 3-5% of patients with cancer. Early diagnosis and treatment is essential to minimise the risk of permanent neurological dysfunction. Guidelines, both national and local, are in place to ensure patients with the condition are treated appropriately.

Aims: To ensure patients with malignant spinal cord compression are treated in accordance with the National Institute for Health and Clinical Excellence (NICE) and local University Hospitals Bristol NHS Foundation Trust guidelines.

Methods: Patients who were referred to the on call oncology Specialist Registrar with suspected or confirmed malignant spinal cord compression were included in this prospective audit looking at a number of standards surrounding the care of patients with suspected or confirmed malignant spinal cord compression. These standards included aspects of the MRI scan used to diagnose the condition, the use of steroids, the time in which definitive treatment was started, and aspects of inpatient care including assessment of bowel and bladder function, thromboprophylaxis and referral to palliative care.

Results: Only two out of the 11 standards were met. Notable shortcomings included the provision of a 16mg loading dose of dexamethasone, delays in awaiting MRI scans and radiology results, delays in starting definitive treatment in a timely manner, not explaining the indications for treating patients with a single fraction of radiotherapy vs a fractionated radiotherapy course and failing to assess thromboembolic risks in patients.
Conclusions: The need to look at referral patterns to neurosurgery was highlighted, along with more education being required regarding care in cases of unstable spinal alignment. This audit highlights the whole array of palliative issues surrounding the common oncological complication of malignant spinal cord compression.

Abstract number: P61
Abstract type: Poster
Audit on the Management of Diabetes mellitus in the Last 48 Hours of Life

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Aim: Diabetes mellitus (DM) is a highly prevalent, life-long condition within the UK population. Changes to the management of DM are necessary for patients at the end of life (EOL) to minimise the risk of symptomatic hyper- or hypoglycaemia and reduce the burden of blood glucose monitoring (BGM). The aim of this audit was to compare the management of patients with DM at EOL to standards set out in local clinical guidelines.

Methods: Retrospective case note review was conducted in a teaching hospital between 1st July - 31st December 2009. Notes included patients >18yrs with type I (TI) or type II (TII) DM who died at least 48hours after admission. Notes excluded patients who died in A&E, acute assessment unit or maternity wards. Data from clinical notes, drug and BGM charts were collated using a proforma and assembled on a database. Seven standards were audited against a target of 100%, and analysed using descriptive statistics.

Results: 50 case notes met eligibility criteria. Clinical teams recognised that 44/50 patients were dying; 42/44 patients had TII DM, 2 patients had TI DM. 8/44 patients suffered ≥1episode of hyperglycaemia (>20mmol/L) and 10/44 had ≥1episode of hypoglycaemia (<5mmol/L) in last 48hrs of life. For TII DM; BGM was stopped in line with guidance in 31% patients, 66% patients taking oral hypoglycaemics had these medications stopped and 50% patients taking insulin had this adjusted in line with guidance. One patient with TI DM was treated in line with guidance.

Conclusion: Management of DM at EOL falls short of recognised standards of care in this hospital. In order to make appropriate clinical decisions it is essential that clinical teams recognise that their patient is dying. Recognition of dying should then prompt changes to the management of patients’ DM. However, some patients are suffering episodes of hyper- and symptomatic hypoglycaemia, having unnecessary BGM and are being prescribed inappropriate medications in their last 48hours of life.

Abstract number: P62
Abstract type: Poster
Re-audit of Professional Interpreter Use in Community Palliative Care Consultations in Inner North East London

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Standard & aims: Palliative patients/families require complex holistic discussions. Using professional interpreters (PI) is the standard for non-English speaking patients needing translation1. The following were assessed:

• Referrer documentation
• Patient demographics, language distribution
• Waiting times
• Interpreter use & outcomes

Methods: Prospective audits were performed by a Hospice Community Palliative Care Team. A standardised audit tool was developed to examine referral forms and palliative care notes of patients assessed as non-fluent in English for one month. Sample:

• First round- All patients
• Second round- New referrals

The latter assessed rationale for not using PI and interpreter value.

First round results: 36 (14%) patients were selected who spoke 11 languages. 36% were male and 85% had cancer and the median (range) of age was 67 (28-82). Waiting time for contacts was up to 13 days. 38 telephone (TC)/ 24 community visits (CV) contacts were made. PI/advocates interpreted for 28 (78%) patients/51 (82%) contacts. 7 patients/10 (16%) contacts used Family Interpreters (FI).

Action plan: Interpreter services were re-commissioned.

Second round results: 6 (16%) patients who spoke 6 languages were selected, correctly highlighted by referrers. 3 were male, 5 had cancer and the median (range) of age was 86 (65-93). Waiting time was up to 7 days. 11TC/8CV contacts were made. 4 patients/6 contacts used PI. Rationale for not using PI included family availability. 6 patients/11 contacts used FI. 82% of interpreter value feedback was positive.

Second action plan: Increased services and staff training in interpreter use are needed to provide appropriate support without delay for palliative patients.

1 National Institute for Clinical Excellence; Your Care, Helping you make decisions, February 2011 http://www.nice.org.uk/getinvolved/patientandpublicinvolvement/yourcare.jsp
Abstract number: P63
Abstract type: Poster

How Can Prescribing Safety Be Assured in a Hospice Setting?

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There is little evidence base on medication errors in palliative medicine and currently what does exist is related to incident reporting. One hospice organisation in England has developed a proactive system for improving prescribing by undertaking prescribing audits 3 times per year against the standards set within the Hospice Medicines Policy. After each audit, educational feedback was provided using variances to standards, to all grades of medical staff, either face-to-face or by email.

A questionnaire was developed to assess the effectiveness of this feedback. Twenty responses were received (64% return) from doctors across all grades. 95% were aware that the prescribing audits are carried out; 75% remembered receiving feedback and of these, all found this feedback to be either ‘quite useful’ or ‘very useful’. More importantly, all found this to be a non-threatening method of improving prescribing. 65% of respondents could provide an example of how the prescribing audit feedback has improved their prescribing.

Specific areas in the prescribing audits were identified as requiring further development. Suggestions were made on how the prescribing audits can be improved in the future and included:

- calculation of a variance rate per grade of medical staff, which would allow accurate comparisons between staff grades
- development of the email feedback system to better reach sessional staff
- introduction of a prescribing assessment for medical staff at induction using results of the audits, which would highlight common variances with the aim of promoting standards in the future.

The aim of this study was to demonstrate that the development of prescribing audits complements the incident reporting system by highlighting issues with prescribing that incident reporting may not always expose. This proactive method has shown to be a non-threatening educational tool for improving prescribing habits in a hospice setting.

Abstract number: P64
Abstract type: Poster

Prescribing in Palliative Medicine - Off-license, Off-label or just Confused

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Background: Regulatory authorities license medications with the ensuing legal liability then spread between prescriber and sponsor. The use of unlicensed medications (off-license) or licensed medications for unregistered indications, formulation or routes (off-label) is common practice, especially in palliative medicine. This has implications for poor prescribing practices, adverse events and medico-legal implications. The aim of this national survey was to determine which off-license and off-label medications were being prescribed most frequently by palliative medicine clinicians in Australia.

Methods: A cross-sectional online survey was sent out to Australian palliative medicine clinicians. Participants were asked “Please list the top three licensed drugs for un-licensed use / routes that you use, their indication, and routes of administration.”. Drugs and indications were categorised into off-license, on-license but off-label, or on-license and on-label according to criteria set by the national regulatory body.

Results: One hundred and five participants responded with 236 proposed off-license drug/indication combinations. Of these combinations, 72/236 (31%) were on-label, 118/236 (50%) were off-label, and 45/236 (19%) were off-license. For the thirty-six drugs listed, 12 drugs were used on-label, 26 off-label, and 2 off-license (some drugs had more than one indication and thus contributed to the counts in more than one category). The five most commonly nominated drugs as used off-label were ketamine, levomeppromazine, haloperidol, octreotide and cyclizine.

Conclusion: The fact that 31% of proposed off-label prescribing were on-label suggests that clinicians have poor comprehension of the licensing for medications they are prescribing commonly. In turn, this may reflect a poor understanding of the evidence base for clinical prescribing, issues with access to medications, and its potential medico-legal implications.

Abstract number: P65
Abstract type: Poster

Does Standard End-of-Life Documentation in an Independent UK Hospice Meet the Goals Set Out in the Liverpool Care Pathway?

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Aims: To establish whether end-of-life care documentation (multidisciplinary care plan and progress notes) in a UK
Conclusions: The LCP provides a framework of best practice for the dying phase and has been adopted in many UK hospitals. It is not commonly used in UK specialist palliative care and many hospices prefer to use locally-designed end-of-life care plans. In this unit, current documentation does not include all the LCP initial assessment goals and does not support the documentation of ongoing assessment of symptoms. Standardised documentation, such as the LCP, may help to improve standards.

Abstract number: P66
Abstract type: Poster

Diagnosing Neuropathic Pain in Patients with Cancer: Comparative Analysis of Recommendations in European Guidelines with the LinkER Procedure


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Neuropathic pain is a prevalent symptom in patients with cancer. In a previous study, 9 clinical practice guidelines (CPGs) were identified dealing with neuropathic pain treatment in cancer patients. The quality of these guidelines largely varied. We hypothesized that quality differences are explained by differences in supporting evidence. In this study, we compared specific diagnostic recommendations in these CPGs in relation to the selected scientific references.

We developed a procedure to classify references and guideline recommendations in CPGs to study the link between evidence and professional decisions: the Link between Evidence and Recommendation (LinkER) procedure. All references were analyzed with SPSS 16.0.

Nine CPGs fulfilled the criteria: 5 were created by professional collaborations like oncology or pain societies and 4 under responsibility of a national organization specialized in guideline development. A total of 146 references (78 after the year 2000) could be selected of which 74 (51%) were about cancer conditions. Although a half was about the utilization of tools or clinimetric articles, mostly a clinical examination was encouraged for the diagnosis of neuropathic pain in cancer but no specific scale was proposed except in two guidelines. More than 30 questionnaires and tools were proposed for diagnosing neuropathic pain. There was no self-citation but references about other CPGs were rare.

The link between the references chosen and the recommendation was unclear: differences are not only explained by the supporting evidence but by the guideline developers. We recommend

(1) a detailed definition of neuropathic pain in guidelines in cancer conditions,

(2) the use of specific screening tools in order to improve the detection and diagnosis and hence, the treatment of neuropathic pain in cancer patients.

A European strategy to reach international consensus is needed as the levels of recommendations varied highly between CPGs.

Abstract number: P67
Abstract type: Poster

Burden and Omission: Medications Prescribed But Not Administered within a Specialist Palliative Care Unit

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Aims: Both polypharmacy and drug omissions (DO) i.e. drugs prescribed but not administered, may impact on quality of life of inpatients within a specialist palliative care
unit (SPCU). This review aims to determine the number of drugs prescribed and the frequency and nature of DO.

**Methods:** A retrospective chart review of regularly prescribed oral, enteral and nebulised medications was undertaken for 35 consecutive admissions in 2011.

**Results:** All 35 patients had cancer (23 males, median age 67, 43% died during admission). Patients were prescribed a median of 8 drugs on admission (range 2-17), 10 upon discharge (range 4-21) and 1 at time of death (range 0-15). During 650 admission days, 10902 drug doses were prescribed. 9% of these were not administered. The most frequent DO were laxatives (25%), mouthcare (17%) and nebulised drugs (10%). Analgesics and anti-emetics were less likely to be omitted. 32% of DO were due to the patient being asleep/drowsy and 29% due to patient refusal. Drugs were not available in 8% of DO. In 112 episodes, a drug was omitted for at least 24 hours with no medical documentation about this in 36% and no change in prescription in 77%. 32 episodes of DO lasted at least 72 hours prompting drug discontinuation in 40%. No harm as a result of these omissions was evident. While fewer drug doses were prescribed for patients who died during admission, the proportion of DO was higher (19%) than for those discharged (6%). DO increased in the last week of life (39%).

**Conclusions:** Polypharmacy is prevalent among SPCU inpatients, more so in patients being discharged. 9% of drugs were omitted with the frequency of DO increasing in those who were dying. Nursing staff administering drugs appear to select more ‘important’ drugs to administer if a patient is not able to manage all of their medications. Daily focused drug chart review should help to reduce and rationalise medication burden, reduce staff time, medication costs and improve patient safety.

**Abstract number:** P68
**Abstract type:** Poster

**A Retrospective Chart Review of the Practice and Documentation of Palliative Sedation on an Inpatient Palliative Care Unit**

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**Background:** Palliative Sedation (PS), the continuous use of sedating doses of medication to reduce consciousness and relieve refractory symptom distress in end-of-life care, is ethically acceptable if administered according to standards of best practice. Adherence to clinical guidelines may prevent aberrant and inappropriate use of PS.

**Research aims and methods:** As a quality improvement strategy, we audited the practice and documentation of PS on our 36-bed inpatient palliative care unit (PCU). A pharmacy database search of all patient admissions in 2008 identified those for a subsequent chart review who received either a continuous infusion of midazolam (≥10mg/24 hours), regular parenteral dosing of methotrimeprazine (≥25mg tid) or regular phenobarbital. Documentation levels of the process, medication use and patient monitoring were collected using a data extraction form based on current international PS standards.

**Results:** Of the 456 patients admitted, 93 (20.4%) received PS for a median of 2 days (range 0-18). All patients had a “do not resuscitate” order prior to initiation of PS. There was marked variation in the initial sedating medications used for PS: 54 (58%) patients started on a single agent and 39 (42%) on multiple agents. Forty (43%) patients were started on midazolam alone with a mean daily dose of 21.4mg (standard deviation 24.6). Interpretation and comparison of data was difficult due to the apparent lack of a consistent operational definition of PS. Patient records had no specific documentation in relation to PS initiation, clearly identified refractory symptoms, and informed consent in 60 (64.5%), 43 (46.2%) and 38 (40.9%) charts, respectively.

**Conclusions:** The lack of documentation and standardized practice of PS on our PCU highlights the need for further research and use of clinical practice guidelines. No funding source

**Abstract number:** P69
**Abstract type:** Poster

**A Survey for Barriers to and Benefits of Quality Improvement Projects and Assessment Tools as Perceived by Palliative Care Services**

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**Objective:** To identify dominant perceived barriers and benefits which impact on the implementation of quality improvement projects by palliative care services in an Australian state.

**Methodology:** A structured questionnaire was developed from in-depth interviews with 5 targeted palliative care providers from diverse clinical and administrative backgrounds. The questionnaire explored the relevance of 9 commonly perceived barriers and 8 benefits. Three questions were added to explore respondent’s impression of
the organisation’s interest and the value given to the service providers’ efforts to implement these tools and projects. The survey was distributed online to 60 service providers in the state.

**Results:** A total of 38 services responded to the survey with 68% from community services, 13% from consultancy services, 18% from inpatient services and none from day hospices.

Dominant benefits attributed to the use quality improvement projects were ‘upskills staff’, ‘demonstrates care practices’ and ‘enables benchmarking’. The main barriers were ‘leads to extra work for staff’, ‘lack of IT support’ and ‘lack of ongoing funds to support data entry’.

Cluster analysis of responses classified all service providers into 3 groups. The **Enthusiast** group hold positive views on all barriers and benefits and highly value related effort invested. The **Conservative** group don’t perceive barriers as roadblocks but also do not see great value in the benefits. The **Cautious** group hold moderate views on almost all barriers, benefits and values. Services with 6-20 staff members are most likely to fall in the **Enthusiast** group.

**Conclusion:** To successfully implement new quality improvement projects, appropriate solutions are required to solve main barriers or concerns faced by services, especially the concern around ongoing funding and sustainability. **Enthusiast** group services are ideal to lead quality improvement projects.

**Abstract number:** P70

**Abstract type:** Poster

**Comparative Analysis of European Recommendations and Evidence Analysis of Treatment of Neuropathic Pain in Cancer Patients with the LinkER Procedure**

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In a previous study, the quality of the development process of European Clinical practice guidelines (CPGs) about the treatment of neuropathic pain in patients with cancer was assessed with the AGREEII instrument. We found huge differences between and within CPGs. In this study, we used the same CPGs to compare recommendations in CPGs about this topic, in combination with the supporting literature.

Guidelines from European countries that contained at least one paragraph on treatment of neuropathic pain in cancer were included. We developed a procedure to classify references and guideline recommendations in CPGs to study the link between evidence and professional decisions: the link between Evidence and Recommendation (LinkER) procedure. All references were analyzed with SPSS 16.0.

Nine CPGs were eligible for further analysis. In all CPGs amitriptyline was mentioned as the drug of first choice, but in six guidelines ex equo with pregabalin or gabapentin. Opioids were proposed only for nociceptive pain. Thirty-three out of 163 citations (20%) were based on studies with cancer patients. Seven CPGs did not argue the indirect evidence due to extrapolation of study results from non-cancer to cancer patients.

Overall, 80% of the recommendations were based on studies in non-cancer patients. The majority of guideline development groups extrapolated these results to formulate recommendations for cancer patients with neuropathic pain without reservations. This might lead to avoidable harm and higher costs. We recommend to collect specific recommendations for the treatment of neuropathic pain in cancer patients and their supporting evidence within an international expert group.

**Abstract number:** P71

**Abstract type:** Poster

‘Taking the Pain Out of Bereavement’ - An Assessment of Bereavement Services in South West Uganda

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**Background:** In South West Uganda palliative care services are limited. One hospice operates an outpatient service and patients travel up to 200km for clinical review and to collect medication. A bereavement service is offered and consists of a home visit by the hospice team (limited to a 20km radius) during which a financial contribution is offered, and an annual multi-faith memorial service for all bereaved families.

**Aims:**

(i) To understand how the term bereavement is interpreted in this region and

(ii) for the first time to investigate the appropriateness and acceptability of the current bereavement service within this cultural setting.

**Methods:** This qualitative study used semi structured, digitally recorded focussed group discussions to elicit the
thoughts and views of three stakeholder groups; clinical staff (10), bereaved family members (10) and community volunteer workers (CVWs) (7). Thematic analysis was carried out for transcribed data.

**Results:** It was found that for the majority, bereavement encompasses a short period of time, often starting before death and extending not far past the burial ceremony. After death the main focus of concern was with the practical and financial arrangements of the burial itself as opposed to the emotions experienced by bereaved relatives. The discussions revealed the importance of a physical presence to convey a sense of caring and support. The bereavement visit was therefore felt to be culturally appropriate by all stakeholder groups and had both practical and emotional benefits. The financial contribution offered, although welcomed, was not seen as the key function of this visit.

**Conclusion:** The evidence supports the continuation of the current bereavement service. The authors would suggest that the financial contribution could be stopped or made discretionary and that there may be a role for CVWs to help increase the number of families receiving a bereavement visit.

**Abstract number:** P72  
**Abstract type:** Poster  
**Changes in Parents after the Death of a Child**

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**Aims:** Few studies have compared multiple perspectives of changes experienced by parents after a child’s death. This study used interviews with bereaved parents and siblings to examine changes in parents during the first year after the death of a child to cancer.

**Methods:** Mothers (n = 36), fathers (n = 24), and siblings (n = 39) from 40 families were recruited from three hospitals in the U.S. and Canada 3-12 months post-death (M = 10.7, SD = 3.5). Semi-structured interviews with open-ended questions were conducted in the home with each participating parent and sibling separately. Content analysis identified emerging themes, and frequencies were compared between each paired set of reports (mother vs. sibling, father vs. sibling, mother vs. father).

**Findings:** Parents and siblings identified two major categories of change experienced by bereaved parents. Parents experienced changes in their relationships (e.g., family, others), and personal life (e.g., emotions, perspectives, behaviors, work, physical, spirituality, and something missing). Some parent changes were positive while others were seen as negative. Differences and similarities between parent and sibling reports will be discussed. Parents and siblings identified two major categories of change experienced by bereaved parents, characterized by positive as well as negative subtexts. Ninety-four percent of mothers, 87% of fathers, and 69% of siblings reported parental changes in at least one of these categories. Parents reported changes in priorities while siblings reported perceiving no changes in priorities, but did report more sadness in parents since the death.

**Conclusion:** This study contributes to the state of science on bereavement care. Practice implications will offer guidance to improve aftercare for parents and their families. Additional research is needed to further describe needs of bereaved parents and to develop strategies to promote helpful aspects of change experienced by bereaved parents.

**Abstract number:** P73  
**Abstract type:** Poster  
**Palliative Care Knowledge and Skills of Junior Doctors: Building the Evidence**

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**Background:** In our team, we have first year doctors rotating through specialist palliative medicine. Based on locally identified need and the risk of potential longer term psychological impact, we introduced a support programme. Concurrently, we looked at wider evidence for such a programme, by reviewing the literature and surveying senior palliative medicine medical views.

**Aims:**

1. To perform a literature review of junior doctor experiences of caring for patients with palliative care needs
2. To gain the views of senior palliative medicine doctors on the timing and delivery of palliative care training in our region

**Methods:** We performed a literature overview, and the results informed questionnaire design (web-based survey using an Online Survey tool). We asked senior doctors for their views on the general palliative care knowledge and skills of junior doctors, and on junior doctors working as part of a specialist palliative care team.

**Results and discussion:** There is a paucity of recent papers on this subject, but all underscore the importance of palliative medicine training, and support the local programme.

24 (77.4%) of the 31 senior doctors responded to the survey. Nine (37.5%) indicated they had junior doctors (in the first two years of clinical practice) in their teams.
A significant percentage (60.9%) (n=14) felt that doctors during the first 2 years after completing undergraduate medical training did not have sufficient general palliative care knowledge and skills as would be expected at that level.

When asked to consider if they agree with the view ‘that if a junior doctor is doing a specialist palliative care rotation very early in their career, it may lead to psychological morbidity’ 4 (16.7%) agreed with the view, whilst 16 (66.7%) did not.

We discuss the impact of the findings on our local programme as well as on wider palliative care education delivery. We propose next steps.

This project was done as part of Dr Tyler’s academic rotation.

Abstract number: P74
Abstract type: Poster

Education and Training in End of Life Care for Health and Social Care Professionals in North West England: A Scoping Exercise and Gap Analysis
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Aims of study: To scope the nature and content of education and training in end-of-life care for health and social care professionals in North West England; To identify gaps in existing provision and priorities for future educational initiatives.

Methods: An online survey of University-based educational provision in North-West England (n=7 Universities) and health and social care provider-based training initiatives (n=48 provider organisations) to ascertain the extent and nature of educational provision and coverage of contemporary policy, best practice initiatives, care pathways and key interpersonal skills;

An online survey of health and social care professionals (n=446) to ascertain their views regarding their preparedness for delivering end-of-life care and perceived gaps in their education and training;

Focus groups of health and care staff (n=21); people receiving end-of-life care (n=16) and carers of such people (n=16) to provide further information regarding staff’s preparedness for end-of-life care and education and training needs.

Results: Education and training was wide-spread but varied widely in extent and content. Key learning methods were discourse and discussion but skills training was less formally evident. Contemporary best practice and policy initiatives were widely but not universally addressed. Staff’s preparedness for end-of-life care varied with role but many staff identified additional learning needs, particularly those is non-specialist roles. Awareness of policy and best practice was not universal. Patients and carers reported mixed experiences of care which they perceived to be the result of poor skills preparation, attitudinal barriers and a lack of co-ordination.

Conclusion: Whilst much education and training related to end-of-life care is on offer in North West England, best practice is not always being addressed. Staff overall require greater awareness of contemporary policy and practice initiatives and enhanced interpersonal skills.

Abstract number: P75
Abstract type: Poster

Constructing a Post-graduate Palliative Care Curriculum: The Israeli National Palliative Care Training (INPACT) Experience
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Aims: The Israeli National Palliative Care Training (INPACT) Program is a collaborative program between academia, Ministry of Health, and other relevant health care organizations and associations in Israel that was launched in 2006. Its goal was to develop and implement educational programs for multidisciplinary health care teams at all levels of care in order to expand the scope, and the quality of palliative care provided throughout the country.

Methods: The presentation will describe the program, the process of the development of its curriculum, and the methods used for its evaluation. An innovative ten-step-process for the development of the curriculum will be presented. We also will present the pre and post evaluation of 219 professionals who participated in the first eight courses.

Results: Three months following completion of the course we evaluated to what extent the knowledge and skills gained were applied in the day-to-day work of the participants. Almost one third noted a very high use, and almost half a high use.

Conclusions: Overall, the program led to an increased awareness to palliative care and an important improvement in knowledge, and skills in the ability to provide palliative care.
Abstract number: P76
Abstract type: Poster

Knowledge and Attitudes Concerning End-of-Life Care in Medical Education - A Survey of 5th Year Students in a German University Hospital

van Oorschot R., Mehdorn A.-S., Niederle R.

Aims: Palliative medicine will be an obligatory part in the curriculum of medical degree as of 2013. To up to now, we offer a seminar entitled “palliative care in geriatrics” and a training how to bring over bad news using standardized patients. In order to improve the subjects of the new regular seminar and to avoid duplications in the curriculum a survey was carried out.

Methods: In October 2010 the fifth year students received a shortened german version of the survey “status of medical education in end-of-life Care” (Sullivan et al 2003).

Results: The questionnaire was given to all 92 students in the first obligatory class on geriatrics. 95% returned the questionnaire (n=88). Most students (97%) had a positive view on physicians responsibilities to help patients at the end of life to prepare them for death and on physicians responsiblities to provide bereavement care to patient’s family members after death (79%). 79% answered that they have deficits in knowledge concerning alleviation of dyspnoe, recognizing different kinds of pain and their management. 42% of the respondents felt not very well prepared for bringing bad news, 58% to talk to patients about their fears of dying and deal emotional reactions of patients or families. 70% had deficits in handling spiritual issues in end-of-life care. To accompany dying people or their relatives with migration background was also difficult for 80%. To make an end-of-life decision 76% felt not very well prepared for, 84% are not well prepared to answer questions concerning euthanasia.

Conclusion: Students consider the care for critically ill patients a very important task for the physician. Even worse than the ability to alleviate symptoms they appreciate their ability to provide psychosocial care at the end of life and for end-of-life decisions. Positive effect of the communication training is seen. The survey will be repeated in October 2011. Results and conclusions will be presented in the lecture.

Abstract number: P77
Abstract type: Poster

Can e-Learning Help Surface or Change Medical Students’ Attitudes towards Palliative Care, Death and Dying?

Gibbons J., Williams J., Cooke J., Alder D., Forbes K.

Aims: e-Learning tutorials are usually used to teach knowledge and skills in medicine. Professional attitudes are important in many areas of medicine, but particularly so in palliative care, where seeing death as failure, therapeutic nihilism, avoiding dying patients, and fears about opioids can all influence patient care adversely. The literature suggests that medical students have misconceptions about palliative care, and articulate anxieties and expectations similar to those of the lay public. No studies have explored the use of e-learning tutorials and attitudes.

Methods: e-learning tutorials were produced by final year medical students about palliative care topics of their choice and developed further by the departments of Palliative Medicine and Medical Education. We performed a mixed methods study to evaluate whether these tutorials enable students to consider their attitudes and/or teach attitudes. As part of each e-learning tutorial, students were asked to write reflective notes on what they had learnt.

Results: 133 students wrote 1012 reflective comments on five tutorials. We analysed 499 of these comments using a qualitative coding system. 322 (65%) of the 499 responses written by senior medical students revealed reflection on an attitude relevant to the scenarios presented within the e-learning tutorials. Of these 43% made a general reflection on a relevant attitude, 37% reflected on their own attitude/s and 19% indicated a change in their attitude following the e-learning tutorial.

Conclusion: Our findings suggest that e-learning can surface attitudes and may encourage attitudinal change about palliative care for final year medical students. The results of this reflective analysis will be presented and discussed.

Abstract number: P78
Abstract type: Poster

Palliative Care for People with Motor Neurone Disease: How Effective Is an Educational Program for Service Providers?

Aoun S., Kristjanson L., McConigley R., Colyer S., O’Connor M., Harris R., Deas K.

Aims: e-Learning tutorials are usually used to teach knowledge and skills in medicine. Professional attitudes are important in many areas of medicine, but particularly so in palliative care, where seeing death as failure, therapeutic nihilism, avoiding dying patients, and fears about opioids can all influence patient care adversely. The literature suggests that medical students have misconceptions about palliative care, and articulate anxieties and expectations similar to those of the lay public. No studies have explored the use of e-learning tutorials and attitudes.

Methods: e-learning tutorials were produced by final year medical students about palliative care topics of their choice and developed further by the departments of Palliative Medicine and Medical Education. We performed a mixed methods study to evaluate whether these tutorials enable students to consider their attitudes and/or teach attitudes. As part of each e-learning tutorial, students were asked to write reflective notes on what they had learnt.

Results: 133 students wrote 1012 reflective comments on five tutorials. We analysed 499 of these comments using a qualitative coding system. 322 (65%) of the 499 responses written by senior medical students revealed reflection on an attitude relevant to the scenarios presented within the e-learning tutorials. Of these 43% made a general reflection on a relevant attitude, 37% reflected on their own attitude/s and 19% indicated a change in their attitude following the e-learning tutorial.

Conclusion: Our findings suggest that e-learning can surface attitudes and may encourage attitudinal change about palliative care for final year medical students. The results of this reflective analysis will be presented and discussed.
Aims: Despite a recognised need for a palliative approach to caring for people with motor neurone disease (MND), access to palliative care is often limited and delayed. Education programs for health professionals are recommended to improve knowledge about MND and the integration of a palliative approach in MND care, however there is a lack of available programs to fill this identified gap. This project aimed to improve the knowledge of health professionals about a palliative approach to MND care through the development, implementation and evaluation of an educational program.

Methods: A three-phase study was undertaken after initial consultations with service providers, carers and patients. Knowledge of palliative care and attitudes to providing MND care were measured pre and post delivery of the educational program and one month later via questionnaires. Interviews were conducted six months after the educational program. Non-parametric statistics were used to measure changes in knowledge and attitudes. Content analysis was used to investigate participants’ experience of the program and impact on practice.

Results: The educational program consisted of 6 learning modules. Six one day workshops were held in WA and SA and 78 health professionals participated. Participants demonstrated improvement in MND and palliative care knowledge and attitudes which were maintained at the six month follow-up. Participants indicated that the gained knowledge positively influenced their clinical practice.

Conclusion: A targeted education program improved understanding about end of life care for people with MND, including understanding of physical and psychosocial needs of MND patients, ability to promote dignity and quality of life and better communication with MND patients. Currently, an implementation plan is being developed between the peak bodies of palliative care and MND to ensure widespread uptake of the educational program across Australia.

Abstract number: P79
Abstract type: Poster

Implementation of the EAPC Postgraduate Curriculum Suggestions - The Flemish Experience

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Aims: To evaluate a postgraduate course for doctors based on "Recommendations for the development of postgraduate curricula leading to certification in Palliative Medicine" published by the EAPC in 2009.

Methods: A program of three modules of three days each was set up by a joint effort of three universities together with the Federation Palliative Care Flanders in Flanders, Belgium. The EAPC curriculum suggestions were rephrased as competences to guide the course development. Various didactical techniques were used. Evaluation was done by completing questionnaires after each module:

1. satisfaction questionnaire based on Student Evaluation of Educational Quality
2. self-efficacy scales asking for perceived competence after the module and
3. self-efficacy scales asking for perceived competences before the module (retrospective pretest methodology).

The same self-efficacy scales were presented 6 months after the last module to evaluate long term effects. A second evaluation was done by presenting a vignette of a patient to the participants before the first module and 6 months after the last module. The vignette contained questions focusing on knowledge, skills and attitudes.

Results: 29 physicians (11 GPs and 18 specialists) participated. Overall results of the satisfaction questionnaires was very high. Participants mentioned the multidisciplinarity and interactivity of the small group sessions as most satisfying. Self-efficacy scales showed significant improvement on all competences. Long term results and results from the vignette-test will be available in December 2011.

Conclusions: Multidisciplinary education in palliative care seems to raise perceived competences of doctors. Involvement of other disciplines (e.g. nurses) could be considered.

Abstract number: P81
Abstract type: Poster

The Practical Difficulties and Concerns of Students of Seeking Patient Feedback as a Formative Part of Education

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Aims: To explore the practical difficulties and concerns experienced by students taking a foundation degree in seeking formal feedback from patients and families.

Methods: Twelve students taking two a year foundation degree in palliative and supportive care were interviewed in groups at three time points. Transcribed interviews were analyzed thematically by two researchers.

Results: Difficulties in approaching patients and carers arose in three areas: small number of suitable patients; reluctance to burden patients and families; patients with poor cognitive abilities; high patient turnover; and brevity of care relationship.

Students were very concerned about the balance of burdens and benefits in asking patients to complete a
questionnaire. Students expressed ambivalence as to whether patients and families would give honest feedback and thus of the formative value of the assessment. They were aware of other care satisfaction feedback which was asked of patients by services and others and, as front line providers of day to day personal care, had particular insight in to the impact of these on patients. Their patient centered focus made it difficult to seek something which was not of direct benefit to patients and about which they were unsure would provide effective learning.

A suggested solution was that their mentors or managers gave out the forms to everyone they had cared for over a week long period.

**Conclusions:** Patient and family feedback is considered a key formative educational strategy and is a requirement for clinical training of doctors. Its use in nurse and other health and social care worker training is not established. The experience of students in this foundation degree exposes some of the challenges of this as an educational strategy.

**Abstract number:** P82
**Abstract type:** Poster

**The Leadership Development Initiative: Understanding the Context and Characteristics of 21 International Leaders**

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**Background and aims:** Palliative care is a burgeoning field around the world, with many international physicians now seeking the leadership skills to spearhead the palliative care mission effectively. This study summarizes physicians’ personal leadership styles and perspectives as they began a two-year training program, with the aim to evaluate their baseline context and characteristics.

**Study design and methods:** Physicians (n=21) completed the Leadership Practices Inventory® (LPI) (*The Leadership Challenge*, Kouzes & Posner, 2007) and before completing the first session of the program. The LPI provided percentile rankings of the physicians’ leadership styles using five categories: Model the Way, Inspire a Shared Vision, Challenge the Process, Enable Others to Act, and Encourage the Heart. Within two months after finishing the first training session, the leaders completed semi-structured qualitative interviews to discuss their personal development and current perspectives on leadership.

**Results:** On average, the physicians scored highest on Challenge the Process and Encourage the Heart leadership styles. However, over half of the physicians (n=12) had no scores in the high percentile range for any of the categories. The dichotomy between the high and low scorers was explored using the qualitative interview results. Low scoring leaders were found to more frequently discussed engagement in team work activities, strong morals, how leadership can provide recognition from others, a fear of resisters, and an acknowledgement of “not being ready yet.” High scoring leaders instead spoke more often about their visionary skills and the sacrifices endured as a leader.

**Conclusion:** Upon entering the program, the physicians varied in their initial leadership styles and perspectives. The results are informative for others who may train palliative care physicians and who wish to tailor programs to meet their foundational leadership needs.

**Abstract number:** P83
**Abstract type:** Poster

**Master of Palliative Care Programme - Survey of Graduates**

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**Research aims:** Following the need of a qualified advanced training in Palliative Care Hospice Austria started a Master of Palliative Care (MSc) Programme in 2006 in cooperation with the private Paracelsus Medical University and the conference centre St. Virgil, Salzburg. After 5 years a survey of all graduates was completed to provide directions for future development.

**Study population:** 3548 graduates of the levels 1-3 of the programme, data were collected and statistically analysed

**Results:**
- Level 1: basic interdisciplinary palliative training - 2 semesters: 2105 graduates (1998-2010); 83,5% women, 16,5% men. Professional background: 62% nursing, 21% medicine, 16% other.
- Level 2: advanced specific training, monoclinical for medicine and nursing, multidisciplinary for paediatrics and psycho-spiritual care - 2 semesters: 379 graduates
- Level 3: academic expert, 2 semesters and master of palliative care, 3 semesters: 64 academic experts and 40 masters of Palliative Care so far.

**Conclusion:** The master of Palliative Care programme meets the demands and needs of the field which is mirrored...
Abstract number: P84
Abstract type: Poster

Reaching the Gold Standard: Assessing Psychometric Properties of Palliative Care (PC) Competency Based Instruments for Medical Learners

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Background: Assessing and evaluating how undergraduate, postgraduate and practicing physicians acquire palliative care (PC) competencies is a growing concern. While several PC competency instruments exist across disciplines (e.g. medicine, nursing) the majority have not been compared with other tools, and only a small number have assessed their psychometric properties. The aim of this study was to compare three locally designed PC competency instruments (designed and modified from previous work), with three internationally designed instruments.

Study design and methods: Drawing on an on-going mixed methods design study, undergraduate medical learners and graduate medical residents with a rotation with the PC unit were asked to participate in both pre and post quantitative and qualitative assessments. Quantitative measures included on-line completion of the three locally designed instruments:
1) Attitudes to Palliative Care,
2) Palliative Care Self-Perceived Comfort Scale and,
3) Palliative Care Knowledge Quiz with three internationally designed instruments

Qualitative measures included one-on-one interviews/focus groups with learners about which measures seemed to best assess their knowledge/attitudes.

Results: To date 28 residents and 23 undergraduate medical students have completed all six pre-rotation instruments. Psychometric properties, assessing internal consistency and factorial analysis for each tool have been run, and the results have been grouped and compared according to PC competency. Qualitative interview and focus group data has been analyzed.

Conclusion: Ensuring that psychometric assessment and evaluation tools are rigorously reviewed and tested for validity and reliability enables us to more accurately capture how palliative care competencies are being integrated into medical learners’ knowledge and attitudes.

Abstract number: P85
Abstract type: Poster

The International Visiting Scholars Program: Results of the Physician Qualitative Interviews

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Background and aims: The International Visiting Scholars program was created with the goal of increasing palliative care skills amongst 21 international physicians and provided four weeks of didactic and bedside training. Physicians were trained in basic palliative care, teaching and presentation skills, a population-based model of palliative care, goal setting, and self-care. This qualitative study aimed to understand the direct and indirect impact of the program through semi-structured interviews.

Study design and methods: An average of 6 months after the program, 17 of the 21 physicians completed semi-structured qualitative interviews via SKYPE ©. During the interviews, physicians were asked to discuss their current palliative care activities and reflect on any resulting personal growth and changes in their practice. Grounded theory procedures were used as the foundation for the qualitative analyses. Two coders used consensus to determine the coding matrix (Saturation point =7) and to establish an inter-rater agreement of 95.4%. Themes were entered into QSR-NVIVO for analysis of code frequencies.

Results: As a result of the program, physicians reported (in rank order) increases in:
1) self-care (94%),
2) presentation skills (94%),
3) patient-centered care (82%),
4) communication (82%), and
5) interdisciplinary team work (71%).

100% of physicians indicated that as a result of the program, they felt more connected to other palliative care experts.
around the world and 71% of physicians noted that they now participated in the teaching and education of others. **Conclusion:** International physicians described increases in several palliative care core skills in addition to several professional skills. These results indicate that palliative care can be successfully taught to physicians around the world thereby serving as a potential model for future palliative care training programs.

**Abstract number:** P86  
**Abstract type:** Poster

### The McMaster-Ottawa Team Observed Structured Clinical Encounter (TOSCE)-a Reliable Assessment Tool for Palliative Care Team Collaborative Practice

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**Aims:** The McMaster-Ottawa Team Observed Structure Clinical Encounter (TOSCE) is a new tool that has been developed, piloted and implemented for use as both an assessment tool for achievement of Interprofessional/team competencies, and Palliative Care competencies. The aim of this presentation is to describe the genesis of this tool, the educational research done to date to assess its acceptability, feasibility, reliability and validity, and to describe its use in palliative care education curricula and clinical practice.

**Methods:** This tool was developed based on existing OSCE methods, evaluated according to current educational research psychometrics and is currently being implemented in medical school and other health science curriculums. The data from learner, evaluator, and reliability psychometrics will be shared.

**Results:** The TOSCE has achieved good interrater reliability, content validity and is highly feasible and acceptable.

**Conclusions:** The McMaster Ottawa TOSCE is an excellent tool for formative palliative competency evaluation, and interprofessional team assessment and hold promise for summative evaluations. It can be used by curriculum assessors, evaluators and teams in clinical practice as a reliable method to understand learning achieved around core collaborative practice competencies and specific palliative care core content areas.

**Abstract number:** P87  
**Abstract type:** Poster

### Is Workplace Based Assessment (WBA) in Palliative Medicine Having its Intended Educational Impact? An Evaluative Study of WBA in Specialist Training in Palliative Medicine

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**Background:** Multiple claims have been made for the educational impact of Workplace Based Assessment (WBA) in specialist training yet there is little evidence in the literature to support these.

**Aims:** This study evaluated whether WBA in palliative medicine is having its intended impact and explored possible logistical reasons for any shortfalls found.

**Methods:** This was a mixed method study with purposive sampling. Online surveys of palliative medicine trainees (n=57) and supervisors (n=76) at one UK deanery were conducted plus semi-structured interviews of trainees. Survey data was analysed using simple descriptive and comparative statistics (Fisher’s exact test). Following member checking, interview transcripts were analysed thematically by manual analysis.

**Results:** Survey response rates were 77% for trainees and 66% for supervisors. 86% trainees and 60% supervisors reported that WBA is primarily of use as a record of competence rather than a learning tool. 70% of both groups disagreed or strongly disagreed with the statement that WBA successfully drives learning. WBA was reported by 71% of both groups to improve frequency of feedback, yet by only 39% trainees to improve quality of feedback. Case Based Discussion was reported by trainees and Multi-sourced Feedback (MSF) was reported by supervisors to be both most useful for learning and most likely to change practice. Content validity of Direct Observation of Procedural Skills (DOPS) requirements was identified as a major concern. Reliability concerns included anonymity of MSF feedback and inter-assessor variation. Logistical challenges identified include time and service pressures and lack of training opportunities for DOPS.

**Conclusions:** WBA in palliative medicine is not yet having its intended formative impact. Recommendations for supervisor training include frame of reference training and introduction to educational theory underlying workplace based learning.

**Abstract number:** P88  
**Abstract type:** Poster

### How do GPs Recognize Needs for Palliative Care in their Patients?

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**Aim:** The aim of this study was to explore how GPs in the Netherlands recognize patients’ needs for palliative care.

**Methods:** We conducted qualitative semi-structured interviews with about 25 GPs. These GPs were interviewed about recognition of the needs for palliative care in their patients and how GPs anticipate on these needs. All interview data were analysed qualitatively, with support of the programme Atlas.ti.

**Results:** Signals on the basis of which GPs recognized a need for palliative care were: a strong increase of care dependency, lost of interest of patients in usual activities or hobbies, depressed mood or other mental changes and / or the message from the medical specialist that cure is no option anymore. GPs act proactively when having recognized a need for palliative care in their patients; they plan telephone appointments or visits at the patient’s home regularly. GPs also look forward with the patient and the family what kind of care wishes the patient and the family have, for example with regard to which place and by whom they wish to be cared for in the last phase of life. This pro-active approach in the palliative phase contrasts with the more reactive attitude of the GP in previous phases of the disease trajectory.

**Conclusion:** This study shows that GPs recognize needs for palliative care by several often subtle signals in the disease trajectory. GPs have a pro-active attitude after signalling needs for palliative care in their patients.

**Main source of funding:** ZonMw-Netherlands Organisation for Health Research and Development

**Abstract number:** P89

**Abstract type:** Poster

**Level of Consciousness in Dying Patients. The Role of Palliative Sedation: A Longitudinal Prospective Study**

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**Aims:** The aim of this study is to describe in detail the evolution of the level of consciousness of patients residing in palliative care units from admission until day of death. A comparison is made between sedated and non-sedated patients.

**Methods:** A prospective longitudinal and descriptive design was used. Each patient admitted in one of the 8 participating units was included if they met the inclusion criteria and gave written informed consent. The Glasgow Coma Scale was used to assess the level of consciousness. Descriptive statistics were used to describe the population under study and to attain further detail of the level of consciousness over time. To assess the impact of the initiation of palliative sedation on the level of consciousness, a logistic regression model was used.

**Results:** 266 patients were included. The incidence of palliative sedation was 7.5%. For the group of sedated patients results show that 90% entered the palliative care unit being fully conscious. Two patients were comatose upon arrival. 90% of the patients remained fully conscious up to the day palliative sedation was started. When looking at the effect of palliative sedation on the level of consciousness the analysis strongly suggest that the palliative sedation - as expected- has an impact on the GCS score. Irrespective of the dichotomization of the score the probability of having a lower GCS increases substantially once sedation is initiated. Additionally, results show that once palliative sedation is administered, the level of consciousness gradually goes down up until the day of death.

**Conclusion:** Palliative sedation is nor slow euthanasia nor an ambivalent practice. It is an intentional medical treatment which is administered in a proportional way when refractory suffering occurs. It occurs in extraordinary situations and at the very end of the dying process.

**Abstract number:** P90

**Abstract type:** Poster

**Drug Interactions in Dying Patients**

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**Aims:** Patients at the end of life often receive numerous medications for symptom management. In contrast to all other clinical situations, the aim of pharmacotherapy is strictly focused on quality of life. The aim of this study is to assess the potential of drug-drug interactions (DDIs) in patients in the last weeks of life and to evaluate the clinical relevance in this specific setting.

**Materials and methods:** Charts of 364 imminently dying inpatients of two hospice facilities were reviewed
retrospectively. Drugs prescribed during the last days of life were screened for DDIs by the electronic database of the Federal Union of German Associations of Pharmacists, which classifies DDIs by therapeutic measures required to reduce possible adverse events according to the ORCA system (OpeRational ClAssification of Drug Interactions).

**Results:** Potential DDIs were detected in 223 patients (61%). In multivariate analysis, polypharmacy was the major predictor for DDIs (odds ratio: 1.5, confidence interval 1.4−1.6). The drugs most commonly involved in therapeutically relevant potential DDIs were neuroleptics (e.g. metoclopramide, antihistamines), antidepressants, insulin, glucocorticoids, cardiovascular drugs and particularly non-steroidal anti-inflammatory drugs (NSAIDs). The most prevalent potential adverse effects were pharmacodynamically additive anticholinergic, antidopaminergic, cardiac (QT interval prolongation) and NSAID-associated toxicity (e.g. gastrointestinal, renal).

**Conclusion:** In the context of end-of-life care, the clinical relevance of DDIs differs from other clinical settings. Most DDIs can be prevented, if the prescribing physician considers a few therapeutic principles that were derived from this study. Specifically, this concerns the awareness of (i) futile and (ii) high-risk medications as well as (iii) rational alternatives.

**Funding:** This study was supported by an unrestricted research grant from Mundipharma.

**Abstract number:** P91

**Abstract type:** Poster

**Actual and Preferred Place of Deaths of Cancer Patients in Four European Countries (Belgium, The Netherlands, Italy, Spain): EURO SENTI-MELC 2010**

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**Study aims:**

1) To estimate the actual place of death, preferred place of death and preference meet of cancer patients in four countries;

2) To explore factors associated with ‘preference met’ in place of death.

**Method:** A mortality follow-back study was undertaken in 2010 via representative nationwide sentinel networks of general practitioners (GPs) in Belgium, the Netherlands, Italy and Spain. With a standardized questionnaire, GPs reported on actual and preferred place of death and on aspects and circumstances of end-of-life care of cancer deceased. The association between seven factors (age, sex, GPs contact, communication with GPs on palliative care, provision of palliative care by GPs, patients’ wishes on medical treatment, patients decision making) and preference met in place of death in each country was assessed through univariate logistic analyses.

**Results:** From the 2010 database, 938 cancer patients with non sudden death were identified. Information on place of death was available for 935 patients, for preferred place of death for 379(41%) patients.

Most people die at home (from 35.2% in Belgium to 58.2% in the Netherlands) or in hospital (from 15.9% in the Netherlands to 38.3% in Italy). Home was the most preferred place of death (from 71.3% in Belgium to 90.1% in Italy). The Netherlands has the highest proportion of preference met (90.7%), followed by Spain(90.0%), Belgium(81.4%) and Italy(67.9%). Full provision of palliative care by GPs until death was associated with preference met consistently in all countries (with ORs ranging between 2.3 to 22.6). GPs’ contact with patients in the last week was strongly associated with preference met in Belgium and the Netherlands.

**Conclusion:** Most cancer patients’ preferred place of death is not known to their GPs. This is a missed chance as in most cases where it is known the preference can be met. Timely communication about preferred place of death and other wishes is crucial in cancer patients.

**Abstract number:** P92

**Abstract type:** Poster

**Guidelines for Withdrawal of Ventricular Assist Devices**

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**Background:** Advanced heart failure is one of the most common causes of admission to hospital in Europe. Patients may be treated with cardiac transplantation but, due to an unprecedented shortage of donor organs, some now receive ventricular assist devices (VADs) - mechanical pumps
implanted alongside the heart to augment cardiac output. Patients may be implanted as rescue therapy, for long term heart failure management or as a bridge to transplantation. Some patients now reach end of life with a VAD in situ, either due to device related complications (stroke, infection) or through the development of terminal intercurrent disease such as cancer.

**Aims:** To develop guidelines for the withdrawal of VAD therapy at end of life.

**Issues:** Scenarios will be presented to illustrate a guidelines algorithm we have developed for management of these cases, for example a patient after massive stroke with a device in situ, and a patient in a hospice setting with terminal cancer. Decision frameworks for withdrawal will be described, underpinned by the UK Mental Capacity Act 2005.

Due to the patient’s underlying cardiac output, death will not necessarily immediately follow switching off the device and this should be anticipated and the expectation managed. All devices have in built alarms to warn of device malfunction but these will cause much disruption at end of life. Device specific management with the help of relevant specialists is crucial to avoid distress.

Use of best interests meetings, independent mental capacity advocates and advance care planning are encouraged within our framework.

**Conclusions:** With increasing numbers of devices implanted in Europe, the issue of end of life care in VAD patients will challenge palliative care teams. Expectations must be managed and knowledge of device alarm systems is crucial to avoid distress at end of life. Advance care plans, advocacy and multidisciplinary working are strongly recommended.

**Abstract number:** P93
**Abstract type:** Poster

**Influenza Vaccination for Palliative Care Terminal Cancer Patients - A Preliminary Report**

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**Aims:** Cancer patients have impaired humoral and cellular immunity, and are more susceptible to infections; their immunological response is expected to be less effective than that of healthy people. Study objectives were to assess the immune response to influenza vaccine in terminally ill cancer patients in a home palliative care unit.

**Methods:** During the fall of 2000-2001, 2005-2006, and 2006-2007, terminally ill cancer patients treated by our home palliative care unit were vaccinated against influenza with Vaxigrip. Blood samples were taken before and four weeks after vaccination. Influenza immunological response parameters accepted in the literature were calculated.

**Results:** Eighteen terminal cancer patients were vaccinated against influenza strains predicted for that year; 13 completed the study. The other five patients died within less than a month from the time of vaccination. The serum protection rate increased from 15.4% before to 61.5% after vaccination, and the serum response rate was 53.8% for all the three strains of vaccination. Mean-fold increase was 24.9 for influenza A-H1N1, 15.4 for influenza A-H3N2, and 2.8 for influenza B. Geometric mean titer was increased for influenza A-H3N2 from 8.3 before vaccination to 159.4 after vaccination; for influenza A-H1N1 from 5.2 to 124.3, and for influenza B from 5.7 to 44.6.

**Conclusion:** The results indicate that influenza vaccination is probably effective and can be offered to terminally ill cancer patients with a life expectancy of about three months in a home care palliative care unit.

**Abstract number:** P94
**Abstract type:** Poster

**Aspects of a Good Terminal Care - The Nurses' View**

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**Aims:** In nursing homes, facilities for handicapped people and home care nursing services staff members are often confronted with death and dying. It is known that one of the greatest burdens of staff members is to believe that the terminal care of a patient/resident has failed. Thus it was the aim of this study to find out the criteria by which nurses and nurse managers judge whether they have succeeded in terminal care or not.

**Methods:** During a research project on the effects of the implementation of palliative care in nursing homes, facilities for handicapped people and home care nursing services, one nursing home manager and one nurse or social care worker from each participating organization took part in support groups. At the end of the project three group interviews took place in these groups, each with 20 participants. The interviews lasted around an hour each. The participants were asked to share a personal experience with terminal care which they recall as extremely positive or negative. The interviews were digitally recorded, transcribed and interpreted according to the qualitative content analysis.
Results: Nurses and nurse managers appreciate terminal care, but also are aware that it causes physical and emotional burdens. There are four main factors that influence the quality of terminal care: factors concerning the patient, for example sufficient symptom control, factors concerning the staff members, e.g. relationship with the dying, own values and ideals, the interaction with others, such as communication with colleagues and relatives and framework requirements like the possibility to fulfill the wishes of the dying person and the existence of advanced care planning.

Conclusion: Respondents share common values about terminal care. In the nurses’ view good care for the dying depends on the quality of interaction relationship between those participating, offers for self-care and suitable training and continuing education in palliative care.

Abstract number: P95
Abstract type: Poster

Narratives of Dying with MND/ALS

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Background: Motor Neurone Disease (MND), although rare, is the most common fatal neurodegenerative disease of midlife. It is rapidly and relentlessly progressive with no curative treatment. Death usually occurs within two to five years. There are diverse and conflicting discourses on dying with MND. The dominant discourses are those of the media - a terrible death involving choking and starvation and medical discourses - a peaceful death.

Objective: To document the constructions of dying with MND provided by individuals who had witnessed the death of a relative with MND to address the research question: “What are the constructions of dying with MND provided by family members who witnessed the death of a relative with MND?”

Method: Narrative interview was the primary method of collecting data; data were derived from the narratives of twenty-one bereaved individuals. A combined thematic and structural analysis of narratives was conducted. Narrative inquiry provided a means to develop situation specific understandings and to explore individual constructions of dying with MND/ALS as meaningful, nuanced and socially embedded events.

Results: A central finding of this study is that the constructions of dying with MND, were characterised by plurality and diversity. While almost all of the narratives related to accounts of dying quickly, peacefully and without pain, they were interwoven with experiences of suffering that occurred during the long trajectories of dying related by these research participants.

Conclusions: The narratives of dying with MND related by bereaved relatives were stories of suffering. This suffering was theorised as being both physical and iatrogenic in origin and was related to the intermeshed components of the physical manifestations of MND, and to the systems of health care, and the individuals within this system, upon which the dying person and his or her family were dependent.

Abstract number: P96
Abstract type: Poster

Introducing an End of Life Care Pathway into Multiple Geographically Diverse Locations

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Aims: The End of Life Care Pathway, adapted from the Liverpool Pathway in use in the UK, is being implemented in multiple locations over a large provincial area. An interdisciplinary working group formed in 2005 and composed of palliative care clinicians, educators and administrators adapted the Pathway to local requirements for use in Continuing Care facilities. Delays occurred due to healthcare restructuring. The Pathway was completed in 2010. As part of an organizational End of Life Care strategy, we are implementing the use of the Pathway, starting with our rural facilities. Our aim is to evaluate the startegy for implementing the Pathway and the local uptake.

Methods: The Pathway was introduced to one urban and nine rural sites from November 2010 to March 2011. One urban site had participated in an earlier pilot project. Ongoing education and support for these sites is provided by 1.4 FTE Clinical Nurse Educators. To date, 33 presentations to over 300 staff have occurred. Data collection includes 1) number of deaths at each site and number of deaths where the Pathway is used 2) number of educational sessions, number attending and disciplines represented 3) factors influencing successes and barriers to the desired outcomes 4) anecdotal comments from staff, residents and families regarding experiences with the Pathway.

Results: The data presented will represent June 2011 to May 2012. It is recognized that implementing change is always a challenge. To date, about 16% of deaths have used
the Pathway. The greatest successes are occuring where there is a commited champion. When it is used families and staff are providing very positive comments. Barriers to use are influenced by such factos as staffing shortages and conflicting priorities.

**Conclusions:** It is anticipated that the outcomes will indicate that the use of the Pathway will improve end of life care. Successes and challenges will be indentified, as well as support required to continue to implement this change.

**Abstract number:** P97  
**Abstract type:** Poster

**Why do Palliative Medicine Patients Attend the Emergency Department? Avoidable or Unavoidable?**

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**Introduction:** Emergency Department (ED) visits made by patients with advanced illnesses in the last weeks and days of life can be very distressing, both to patients and their families. For some patients these visits may be unnecessary and potentially avoidable, in particular where a decision has been made to maintain the patient at home for end-of-life care. With an understanding of why patients attend, interventions to avoid these visits may be possible.

**Aims:** We aimed to identify patients known to the specialist palliative medicine service (SPMS) attending the ED over 6 months to determine if these visits were deemed potentially avoidable.

**Methods:** All patients known to the SPMS who attended the ED department between 1st July-31st December 2010 were identified. Data were collected by reviewing patient ED records, in-patient hospice records and home care records. Two physicians subsequently independently assessed whether the visit was deemed potentially avoidable.

**Results:** Thirty-five ED presentations by 30 patients were identified. Eighteen (60%) were male. Mean age 68.7 years (47-89). One patient (3%) made 4 visits and 2 patients (2.5%) attended twice. Twenty-two presentations (63%) were made outside normal working hours. Patients were admitted from the ED following 33 of the 35 presentations (94%). The main reasons for attending were: dyspnoea (n=9, 26%), nausea/anorexia/dehydration (n=6, 17%) and uncontrolled pain (n=5, 14.5%). Fifteen of the 30 patients (50%) died within one month of attending the ED. Twenty of the presentations (57%) were deemed potentially avoidable.

**Conclusion:** Our results highlight that a significant number of palliative medicine patients attend the ED. Appropriate transfer of information to on-call doctors, as well as creating confidence in carers and providing extra practical supports may help avoid unnecessary visits. A comprehensive coordinated specialist palliative care approach may ensure patients do not present to the ED inappropriately.

**Abstract number:** P99  
**Abstract type:** Poster

**The Use of the Edmonton Symptom Assessment Scale to Measure Symptoms at the End of Life**

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**Aims:** The Department of Health’s End of Life strategy promotes integrated care pathways for the dying as a means of improving end-of-life (EOL) care. We designed a pilot study to determine whether a simple EOL care tool could improve the dying experience in an acute hospital setting as perceived by carers.

**Methods:** 40 patients received usual EOL care and 30 patients had their EOL care directed by the EOL care tool. Bereaved carers were contacted a month after the patient’s death and asked to complete the validated VOICES questionnaire.

**Results:** 20/40 questionnaires were returned by carers whose relatives received usual care and 18/30 by carers whose relative received care directed by the tool. Although numbers are small and therefore changes are not statistically significant, improvements were seen in the responses regarding medical and nursing care (43.8% of relatives rated nursing care as excellent in the usual care group compared to 83% in the EOL tool group). Benefits were seen in pain management (56.3% of carers perceived their relative had pain when receiving usual care vs. 28% in the EOL tool group). Improvements were also seen in communication with more relatives feeling they were kept informed about the patient’s condition in the EOL group than in the usual care group. (64% vs. 38%). More carers were present when their relative died following introduction of the tool (43.8% of the usual care group vs. 67% in the EOL tool group).

**Conclusion:** Non-professional carers reported improvements in some aspects of end-of-life care following the introduction of a simple EOL care tool. This needs further testing in an adequately powered trial.
Aims: There is currently no tool available to capture symptom control in the dying. The Edmonton Symptom Assessment Scale (ESAS) has been validated for patient and caregiver-rated scoring of patients’ symptoms, enabling recording to continue as patients deteriorate. However, it has not been used specifically to measure symptoms in the last days of life. The aim was to assess the utility of ESAS in scoring symptoms in the dying patient as measured by completion rates in a ‘before and after’ study investigating the impact of an end-of-life (EOL) care tool.

Methods: 70 patients were recruited; 40 before and 30 following the introduction of the EOL tool. Nursing staff were asked to complete 12-hourly ESAS scores from the time the ‘diagnosis of dying’ was made until death.

Results: 54% of the ESAS forms were completed but some were not fully scored. 77% of patients recruited had an ESAS form completed in the last 24 hours of life. The number of patients with a score for each of the individual symptoms within ESAS varied in both groups. Core EOL symptoms (pain, shortness of breath, nausea, chest secretions and agitation) were scored more frequently when the EOL tool was in place. The frequency of completion of these core symptoms ranged from 75-97% for patients receiving care directed by the EOL tool versus 28-58% for patients receiving usual care.

Conclusion: The proportion of missing data suggests 12 hourly symptom scoring was onerous for ward staff. The improved completion rate for core EOL symptoms suggests either that the introduction of the tool improved the nurses’ ability or confidence to measure symptoms, or that scoring improved because the task was ‘learnt’ during the study. A shortened ESAS containing only core EOL symptoms might have better utility as an outcome measure for the last days of life.

Abstract number: P100
Abstract type: Poster

Health Care Professionals’ Views on Factors Influencing End-of-Life Care in Hospitals

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Aims: The majority of patients die in hospitals, yet care delivered to the dying in the acute setting is variable and the underlying reasons for this are not documented well. We aimed to explore health care professionals’ views on the factors influencing good quality end-of-life (EOL) care in an acute hospital trust.

Methods: Within a feasibility study examining the impact of a simple EOL care tool on the dying experience, we carried out qualitative interviews with health care professionals caring for dying patients.

Results: Five focus groups, nine face-to-face and two ‘think aloud’ interviews were analysed using the framework approach. The emerging themes were: difficulties in diagnosing dying (staff felt that the decision to switch to comfort care was often made late which meant that patients received unnecessary treatments); hospital culture (reluctance to withdraw active treatments; it was “brave” to state a patient was dying); hospital systems (patients moved frequently between wards which did not facilitate diagnosing dying and medical notes did not provide sufficient information to aid junior doctors out of hours when making decisions about sick patients) and the impact of the EOL tool on care (nurses found the regular symptom scoring required by the tool helped them approach patients and families and give more appropriate care).

Conclusion: This qualitative study has identified factors influencing care given to dying patients in an acute hospital setting. We suggest these factors need to be taken into account when trying to improve care for dying patients and in facilitating the use of EOL care pathways.

Abstract number: P101
Abstract type: Poster

The Role of Chaplains in End-of-Life Treatment Decisions and Ethics Consultation

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Background and aim: Chaplains are often consulted in ethically difficult treatment decisions, sometimes even as members of Health Care Ethics Committees. The aim of this study is to discover how chaplains assess their role within ethically complex end-of-life decisions.

Methods: A questionnaire containing 27 items was sent to chaplains who work for German health care institutions. Questions about their role and position concerning ethical issues as well as additional demographic data were collected, which contained amongst others information about the chaplains’ religious affiliation, training and integration within multiprofessional teams. Data was analysed statistically.

Results: The response rate was 59%, 141 questionnaires were analysed. Half of the chaplains were members of an ethics support team. Respondents reported to be confronted with decisions concerning limitation of life-sustaining treatment on average 2-3 times per month. Nearly 74% declared to be satisfied with the decisions made within these situations. However, only 48% declared to be satisfied with
the communication process. One of the main difficulties for the chaplains is the communication process with physicians and nurses as opposed to clergy colleagues. Whenever chaplains were integrated within a multiprofessional team there was a significantly (p≤0.05) higher satisfaction with both: the decisions made and the communication process.

**Conclusion:** Chaplains are often confronted with end-of-life treatment decisions. Although the results of this study demonstrate a relatively high satisfaction rate with the outcome of these decisions, the communication process remains to be one of the major problems. It seems that a clear integration of chaplains within multiprofessional teams (such as Palliative Care teams) increases satisfaction with communication in ethically critical situations.

**Abstract number:** P102  
**Abstract type:** Poster  
**Medical Decision Making at the End-of-Life: Knowledge of Nurses and Nursing Assistants in Long-term Care Facilities**  
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**Introduction:** A growing segment of the elderly die in long-term care facilities. Nurses and nursing assistants play an important role in the communication about medical decision making at the end-of-life in these facilities, where medical doctors are scarcely available. This study portrays the current knowledge of nurses and nursing assistants in long-term care facilities about medical decision making at the end-of-life.

**Method:** A cross-sectional survey tested the knowledge of 164 nurses and nursing assistants in 8 different long-term care facilities in Belgium. Questions dealt with 3 topics: voluntary active euthanasia, symptom control and withholding/withdrawing therapy. In order to identify factors associated with better knowledge a three-way ANOVA was performed.

**Results:** Nurses and nursing assistants scored an average of 6 out of 10 on the knowledge questions about the rights and the possibilities of patients concerning end-of-life care. Especially the knowledge on voluntary active euthanasia was poor, compared to the knowledge on symptom control and withholding/withdrawing therapy. The three-way ANOVA showed that the degree of education (F = 33,15, p < 0,001) and specific training in end-of-life care topics (F = 8,54, p = 0,004) were significantly associated with better scores. Being part of a palliative team had no significant independent effect on the knowledge scores (F = 2,48, p=0,12).

**Conclusion:** There is still room for improvement in the knowledge of end-of-life care of nurses and nursing assistants in long-term facilities. Especially the knowledge on the legal aspects of voluntary active euthanasia was poor. This research shows that specific training can significantly improve the knowledge of the healthcare providers. This can be a useful tool in pursuit to improve end-of-life care for elderly institutionalized patients.

**Abstract number:** P103  
**Abstract type:** Poster  
**Advance Care Planning in Elderly Ill Patients: A Guideline for Healthcare Providers**  
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**Introduction:** Advance care planning (ACP), the communication process by which patients establish goals and preferences for future care, is encouraged as a way to improve end-of-life care. Elderly patients however are not frequently involved in ACP. This guideline wants to help healthcare providers to start exploratory conversations on the subject of ACP.

**Method:** This guideline is based on interviews with 38 seriously ill elderly patients and 21 family members. Interviews were analyzed according to the Grounded Theory approach. The guideline was than fine-tuned by expert opinions, obtained in 3 focus groups.

**Results:** First of all , the healthcare provider has to find out if patients are able to think about their own death. Moments like a cessation of treatment can be crucial in this matter. However patients who can’t deal with this, should be respected. Furthermore if an ACP-process is started with patients who can’t think about their own death, there is a great risk of capturing only superficial opinions, that may differ from the actual wishes of patients at the end-of-life.

Secondly, attention is required for factors that stimulate ACP, like having bad experiences with dying. Carefully questioning these experiences and correcting possible misunderstandings, are important steps.

Expectations and discussions from patients and family members towards the care planning at the end of life are embedded in existing relation patterns. It is recommended to respect these patterns towards decisions at the end of life.

**Conclusion:** This guideline wants to highlight important factors rather neglected in existing guidelines concerning
ACP. Being aware of the ability of the patient to think about one’s death, considering previous bad experiences with dying and realizing that existing relation patterns are important, can substantially improve the quality of ACP.

**Abstract number:** P104  
**Abstract type:** Poster  

**Recent Pulmonary Embolism at Autopsy and Prophylactic Anticoagulation**  
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**Introduction:** The benefits of prophylactic anticoagulation in end-of-life patients with an advanced cancer are still discussed. Our objective was to measure the association between a recent pulmonary embolism (PE) at autopsy and the prescription of anticoagulation (AC).

**Method:** Retrospective study of all the patients with an advanced cancer hospitalized in the palliative medicine division from 2004-2010 that had an autopsy (review conducted in conjunction with the study on the association between pulmonary infection and prescription of antibiotics).

**Results:** 240 patients were included (130 men, mean age: 74±13). Main cancer were: gastrointestinal (75;31%), respiratory (57;24%), genitourinary (50; 21%), breast (21;9%), hematological (10;4%) and other (27;11%). Main co-morbidities were high blood pressure (86; 36%), cardiac disease (74;31%), COPD (26;11%) and diabetes (23;10%). During their last 2 weeks of life, 106 patients had no AC; 30 therapeutic AC (13 for cerebro-cardiac-disease, 11 for thromboembolic disease, 6 for recent PE) and 103 prophylactic AC. During the same period 59 (25%) patients present dyspnea, 9 chest pain (4%) and 2 hemoptysia. At autopsy 49 (20%) had a pulmonary embolism. 19 (38%) of them had prophylactic anticoagulation (P<0.05). In a logistic regression model, while adjusting for the age, gender, main diagnosis, co- morbidities, symptoms, AC, the only independent factors associated with PE at autopsy were the history of thromboembolic disease and therapeutic AC. 26 patients had an associated pulmonary infection. Other causes of death were pulmonary infection (132;55%), other infections (8;3%), advanced cancer (37; 15%), cardiac complications (12; 5%) and other (2;1%).

**Conclusion:** The results of this retrospective study confirm the high rate of PE in this population, also in patient that have AC and should encourage us to pursue other prospective studies to demonstrate the benefit of prophylactic AC for these patients.

**Abstract number:** P105  
**Abstract type:** Poster  

**Association between Pulmonary Infection at Autopsy and Prescription of Antibiotics**  
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**Introduction:** The benefits of antibiotics in end-of-life patients with an advanced cancer are still discussed. Our objective was to measure the association between pulmonary infection (PI) at autopsy and the prescription of antibiotics (AB) during the 2 last weeks of life of patients.

**Method:** Retrospective study of all the patients with an advanced cancer hospitalized in the palliative medicine division from 2004-2010 that had an autopsy (review conducted in conjunction with the study on the association between recent pulmonary embolism and anticoagulation prophylaxis)

**Results:** 240 patients were included (130 men, mean age: 74±13). Main cancer were: gastrointestinal (75;31%), respiratory (57;24%), genitourinary (50, 21%), breast (21;9%), hematological (10;4%), other (27;11%). Main co-morbidities were high blood pressure (86; 36%), cardiac disease (74;31%), COPD (26;11%), diabetes (23;10%) During their last 2 weeks of life, 136 (57%) patients presented a clinical suspicion of infections (97 PI, 14 urinary, 7 digestive, 6 bacteriema). 76 of them received AB (piperacilline-tazobactam:20, cephalosporin:24, fluoroquinolone:17, carbupenem:5, metronidazole:5 , other 6). At autopsy 158 (66%) had a PI. Other causes of death were pulmonary embolism (49; 20%), advanced cancer (37; 15%), cardiac complications (12; 5%); other infections (pyelonephritis) (8;3%), other (2;1%). 3 patients had pulmonary aspergillosis. In a logistic regression model, while adjusting for the age, gender, main diagnosis, co morbidities, blood count, corticoids, antibiotics, the only independent factors associated with PI at autopsy were being a man. There was not statistically significant trend for high blood pressure, diabetes and leucocytes.

**Conclusion:** The results of this retrospective study confirm the high rate of PI in this population; also in patient that received AB. These results should encourage to conduct prospective studies to demonstrate the benefit of antibiotics in this population.
Abstract number: P106
Abstract type: Poster

Legal Euthanasia and Physician-assisted Suicide in the Netherlands: No Apparent Wish to Broaden the Scope of the Law

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Aims: The practice of euthanasia and physician-assisted suicide (PAS) in the Netherlands is regulated since 2002 in the Euthanasia Act. This study aims to evaluate the opinions of physicians, nurses and the general public in the Netherlands on several of the legal requirements for euthanasia and PAS.

Methods: A cross-sectional survey was conducted among physicians, nurses and members of the Dutch general public, followed by qualitative interviews among selected respondents.

Results: 793 physicians, 1243 nurses and 1960 members of the general public completed the questionnaire, 83 of them were interviewed. Most respondents agreed with the requirement of a patient request (64-88%) and with the absence of a requirement concerning life expectancy (48-71%). Furthermore, 24-39% thought that PAS is acceptable for patients requesting it because of mental suffering due to loss of control, chronic depression or early dementia. One third of physicians, 58% of nurses and 77% of the general public agreed with performing euthanasia in case of dementia, based on an advance directive. Interviewees illustrated these findings and supported the Act.

Conclusion: Health care professionals as well as the general public mostly support the legal requirements for euthanasia and PAS. The law permits euthanasia or PAS for mental suffering, but this principle is not widely endorsed. The general public is more liberal towards euthanasia for advanced dementia than health care professionals. We conclude that there is no apparent wish to broaden the scope of the law in Dutch society after eight years of legal euthanasia.

Abstract number: P107
Abstract type: Poster

End of Life Care in Czech Republic from the Perspective of Health Professionals - A National Survey among Representative Sample of Physicians and Nurses

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Method: A representative sample of health professionals (n=1006) in Czech Republic was interviewed by CAWI method (Computer Assisted Web Interviewing) by a professional pool agency STEN/MARK in June 2011 about.

Results: The pain controle in terminaly ill is in Czech health care system- according to HePro - very good, good, poor, very poor in 6%,52%, 30%,3% respectively. The patient’s wishes and preferencies are “always respected”, “mostly respected”; ,,mostly not respected”, „not respected” in 25%, 51%, 18% and 30% respectively. Communication of physicians and nurses with terminaly ill is very good, good, fair, poor, very poor in 3%, 20%, 25%, 42%, 6% respectively. The HePro answered the question „Do you feel competent in care of a dying patient and his family?” yes, mostly yes, mostly not, not in 18%, 69%, 13% and 0% respectively. The HePro were asked to rate the quality of care for the dying patients in different settings. The proportion of answers „very good“ and „good“ for acute care hospital, long term care hospital and in-patient hospice were 52%, 22% and 79% respectively.

Conclusions: The first survey among representative sample of HePro in Czech Republic shows a rather pesimistic picture how the quality of end of life care is perceived by the care providers. One third is convinced that the pain is not well controled and the wishes and preferences of patients are not respected. Nearly half of HePro considers the quality of communication poor or very poor. The quality of care of the dying in acute- and long term care hospital (where nearly 65% of all deaths occure) is put in question by large proportion of responding HePro. The in-patient hospices have the reputation of the place of a good care of the dying.

Discussion: The data show indirectly the existence of a shortage in good quality end of life care within health care institutions in Czech Republic. Further proces - and outcome oriented research about end of life care in different settings is needed.

Abstract number: P108
Abstract type: Poster

Dying Well - Registered Nurses Perceptions of the Phenomenon of a Good Death
Background: The concept of a ‘good death’ is a dynamic and highly subjective process. Despite much research, its understanding is surprisingly lacking. This descriptive qualitative study was directed from a general nursing perspective. While a ‘good death’ has been explored within specialist palliative care services, empirical evidence is absent within non-specialist palliative care services. This study will add to the body of knowledge concerning the nature of a good death.

Objectives:
1) To describe the “Good Death” trajectory.
2) To capture the transitions in the care of the dying.
3) Extrapolate participants’ learning needs in order to facilitate a “good death”.

Methods: Semi structured interviews were used as the sole form of data collection. Participants consisted of eight registered nursing staff from a general medical ward of varying rank, and contextualized within a non-specialist palliative care service in the Republic of Ireland. The concepts of “caring” and “dying” provide the theoretical framework for this study.

Results: Participants identified one core theme of ‘hegemony of tolerance’ and three interrelated themes concerned with: “The Dying Trajectory”, “Delivery of Care and the Fundamental Necessity to Homogenize Basic Care”, and “Management, Resources and the Need for Change”.

Conclusion: As yet there is no prevailing consensus as to what constitutes a ‘good death’ and despite many studies, its understanding is surprisingly lacking. The goal of end of life care ought to be based on the premise that care is holistic, person centred and free from suffering.

Abstract number: P109
Abstract type: Poster

Place of Death after Stroke - The Views of Health Care Professionals on an Acute Stroke Unit

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Introduction: Stroke is the third commonest cause of death in the United Kingdom (UK) and causes significant symptoms and disability. In the UK, acute stroke care occurs in hospital. Previous research suggests that most stroke patients die in hospital; families appreciate stroke unit expertise and rarely consider that patients could die at home.

Aims: To determine what healthcare professionals (HCP) on a stroke unit believe constitutes good end of life care and whether barriers exist to its implementation.

Method: 15 HCP from an acute stroke unit were purposively sampled. Semi-structured interviews were undertaken to examine specific care domains, including place of care. Interviews were recorded, transcribed and analysed using Framework Analysis.

Results: Participants believed it is important for dying patients and their families to have privacy, a comfortable and dignified environment and not to be moved between wards. HCP reported requests from families for patients to die at home were rare and believed patients were often too poorly to travel home. HCP had experience of getting patients with other diagnoses home to die. Perceived barriers to discharge include lack of family support, absence of community nasogastric feeding and delays in funding, commencement of care and delivery of equipment.

Conclusions: Families and patients rarely request discharge home to die. Reasons may include: patient/family choice, impaired capacity, cognition and communication, rapid deterioration, prognostic difficulties, families’ expectations, lack of family, delay in delivery of equipment or package of care, unawareness that patients could die at home.

Recommendations:
• Further research into preferred place of care/death after stroke
• Encourage patients with capacity to discuss place of care
• Discuss dying patients care at multidisciplinary meetings
• Facilitate patient communication
• Improve links with primary care, social care, community palliative care and volunteer organisations

Abstract number: P110
Abstract type: Poster

Spirituality and Faith: Means for Coping with the Effects of Motor Neurone Disease (MND)

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Aims: To explore the personal experience of living with MND as documented in personal illness narratives, written by people diagnosed with the illness and examine the role of spirituality and faith as means of coping with the illness.

Methods: A systematic search strategy was used to identify and locate published and unpublished personal illness narratives written by people diagnosed with MND. Content and thematic analysis was aided by Nvivo 7 software.
Results: First-person accounts of living with MND written from 1986-2005, by 161 individuals, were obtained. Throughout the narratives there is frequent reference to the power of spirituality to impact positively on the illness experience. People refer to the strength acquired from seeking a spiritual understanding of their circumstances. There is a sense of being used for a ‘higher purpose’, being seen as a spiritual example to others. Religious convictions are frequently strengthened following the diagnosis and are sustained by a conviction that ‘God’ will not burden them beyond their ability to cope. Faith is regarded, by some, as a cornerstone in coming to terms with their future. Belief in an afterlife sustains many authors as they recognise the present time as just a small part of a much longer time span.

Conclusions: It is evident within the narratives that people with MND tolerate distress through maintaining hope by belief in a divine entity and through connection with a higher being or with other people, which reflects the importance of relational values in coping with MND. Seeking answers to life’s questions at an existential level enables many individuals to sustain hope and arrive at a sense of peace with their situation. Spirituality should be regarded as an important resource for coping with MND.

Abstract number: P111
Abstract type: Poster

Health Care Professionals’ Considerations Regarding Indications for Continuous Palliative Sedation until Death (CPS)

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Introduction: Quantitative research has shown that Continuous Palliative Sedation until death-practice (CPS) in the Netherlands largely reflects recommendations from the Dutch National Guideline, issued in 2005. We further qualitatively investigated health care professionals’ considerations contributing to the indication for CPS.

Methods: 54 physicians and 38 nurses were interviewed about the last patient in whom they had been responsible for providing CPS.

Results: Factors contributing to the indication for CPS were:
1. Presence of severe symptoms; occasionally one decisive symptom could be indicated, but more frequently the indication was based on a combination of physical, psychosocial and existential symptoms. Sometimes respondents referred to more general notions, e.g. ‘pointless suffering’ or ‘preventing severe symptoms to develop’.
2. Treatment possibilities; most often respondents referred to lack of treatment possibilities, sometimes other treatment was considered futile.
3. Others like:
   - Patient and family factors; e.g. refusal of other treatment.
   - Place of care; e.g. technical devices not available at place of care.
   - Life expectancy; whereas most respondents considered a limited life expectancy an important condition for CPS, some mentioned that the necessity to alleviate severe suffering may prevail over considerations with respect to life expectancy.

Conclusion: A decision for CPS may predominantly be indicated by the presence of severe and refractory physical symptoms in patients with a limited life expectancy. However, in some cases CPS is used to address a more generalized ‘refractory state of severe suffering’ caused by physical as well as psychosocial and existential factors.

Abstract number: P112
Abstract type: Poster

The Evaluation of Relationship between the Quality of Terminal Care and the Level of Disclosure of Cancer in Terminally Ill Cancer Patients Using Support Team Assessment Schedule (Japanese Version)

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Aims: To ensure quality cancer care in the terminal phase, it is important for medical professionals to provide patients and their families with necessary information about the cancer. The aim of this study is to evaluate the relationship between the quality of terminal care and the level of disclosure of cancer in terminally ill patients.

Methods: The subjects were 87 terminally ill cancer patients who died of cancer during the last three years. Disclosure of cancer was classified into four groups: “non-disclosure of the cancer diagnosis” “disclosure of the cancer diagnosis” “disclosure of the life-threatening or incurable illness” and “disclosure of poor prognosis (i.e. limited life expectancy)”. Using the Japanese version of the Support Team Assessment Schedule (STAS-J), we evaluated the quality of palliative care services provided for patients and their families during their final hospitalization.

Results: The numbers of patients in these groups were 8,22,37,20, respectively. Regarding physical symptoms such as pain, fatigue and dyspnea, no marked difference was noted between these groups (p=0.1892). Anxiety felt by the patients and their families was markedly reduced when
they received more information ($p=0.0059$, $p=0.0266$). The degree of the recognition of disease conditions was markedly higher in the groups that were specifically informed ($p<0.0001$). The level of communication was also significantly higher in the groups that received precise information ($p<0.0001$). When patients were informed of their disease conditions and prognosis:

1) they openly communicated with their families;
2) medical professionals promptly shared accurate information with each other; and
3) medical professionals provided patients and their families with necessary information.

Conclusions: In addition to informing patients of cancer, the provision of more precise information, including disease conditions and prognosis, led to an improvement in the quality of terminal care.

Abstract number: P113
Abstract type: Poster

Public Preferences and Priorities for End-of-Life Care: Case Study in Namibia

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Background: Globally, end-of-life (EOL) care needs of populations are growing. To help ensure care services are responsive to what people expect, want and need, it is imperative they take into account public, patient and family carer preferences. This study explored the EOL care, death and dying priorities and preferences of the Namibian public.

Methods: Using a population-based street survey, data were collected in the capital in late 2010. The interview schedule included questions adapted from a European Union (EU) Commission-funded project (i.e. PRISMA) and gathered socio-demographic data as well as EOL preferences and priorities. Data were analysed using descriptive statistics and bivariate logistic regression.

Results: The survey included 200 respondents (response rate=91%), with equal proportions of men and women. This sample was largely urban based (95%) and much younger (mean age 27; SD 7.5) than the EU PRISMA survey sample (mean age 51; SD 16.0).

Hospital (47%) and home (32%) were the most preferred places of death. Home (56%) and hospital (22%) were also the least preferred places of death. Most important EOL priority was keeping a positive attitude (64%); most important care-related aspect was having as much information as wanted (72%). Sixty-four percent wanted their EOL care to focus on improving quality of life (QOL). Wanting to keep a positive attitude at the EOL was the only factor weakly associated with preference for a home death ($OR=1.827$, $95\%CI=0.977-3.416$, $p=0.059$).

Discussion: This study largely determined the hypothetical views of an urban based, young and healthy sample. Participants highly valued improving QOL for the time left to live, requiring greater attention to palliative care alongside potentially life-extending treatments. The desire for information requires sensitive approaches to meet patients’ needs. The population is divided into preferring to die in hospital or at home, revealing potentially underlying concerns.

Abstract number: P114
Abstract type: Poster

Post-mortem Care in a Palliative Medical Unit

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Since 1995 members of the Palliative Medical Unit (PMU) at Trondheim University Hospital have systematically registered how relatives interact with the deceased and with health care staff. A standardized registration form with some twenty questions, initially named ‘Routines at the time of death’ has been developed. This tool is utilized and filled out by the PMU nurse in charge of the patient and family. In addition to registration, the form functions as a checklist for nurses in connection with their interventions. The implementation of the tool was founded in an aspiration to safeguard relatives’ need to be present and to participate during end-of-life care and death of their loved one based on the tenet grief support (Petersvik, 1997, p. 46). The registration form has been revised and extended. The latter form contains 33 items. Data from registration 3 involves 400 registration forms, representing 71.1% of all deaths at the ward during this period. The data is analysed in SPSS, mainly covering frequency distribution. In our analysis some corresponding items from registration 2 is compared with registration 3. This comparison gives us some indication of how the standardisation of post-mortem care in the PMU has change over time. Our findings confirm that relatives where informed about signs of imminent death in approximately in 90 % of cases. This figure has been stable over time. This find confirms our assumption that this information is given in order for relatives to have the chance to participate on their terms. Our data
indicates that relatives are more often present at the time of biological death. Some of the post-mortem routines are slightly changed over time. The average time the deceased stay at the PMU after biological death is 10 hours.

Abstract number: P115
Abstract type: Poster

A User Group Formed to Help Guide a Research Study Evaluating a Hospice at Home Service

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Aims: A new hospice at home service was set up and a research study was undertaken to evaluate it. The service was designed to meet the national government “End of Life Care” agenda. The research project obtained ethics approval. The service commenced incrementally over 18 months across three hospices from 1st January 2010, eventually

The service commenced incrementally over 18 months

Care” agenda. The research project obtained ethics approval. The service was designed to meet the national government “End of Life

was designed to meet the national government “End of Life Care” agenda. The research project obtained ethics approval. The service commenced incrementally over 18 months across three hospices from 1st January 2010, eventually serving a population of 600,000. A User Advisory Group (UAG) was convened and met regularly for the duration of the project. The primary purpose of the UAG was to advise and comment on all aspects of the research evaluation, to assist the researchers to obtain meaningful data and to be fully aware of the potential issues and concerns of patients and carers involved in the research.

Methods: The UAG was comprised of patients, carers and bereaved carers. The recruitment of members for the UAG required specific attention to the sensitive issues involved. Clear terms of reference were communicated to the members so that they understood the areas to be discussed which included openly talking about death and dying. Attention was paid to the environment and administration of the User Group to provide safety and to inspire confidence.

Results: Attrition was an issue but there was surprisingly good continuity in the UAG membership. Members of the group confirmed the appropriateness of asking patients about their preferences for place of death. They believed that access to care in the home at the end of life was very important and it was perceived that Hospice care is “death specific” and dedicated in a way other services are not. The questionnaires which carers were asked to complete as part of the research were comprehensible but daunting - UAG members gave valuable advice on how to increase the response rate of the questionnaires.

Conclusions: The UAG members were courageous in providing important contributions to the successful completion of the research.

The source of funding: National Institute Health Research through the Research for Patient Benefit programme (in the UK)

Abstract number: P116
Abstract type: Poster

Practice of Palliative Sedation at Home at the End of Life: A Comparison with Current Data in the Literature

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Introduction: A proportion of patients in a state of terminal illness is suffering from intolerable symptoms at the final stage, which would have required palliative sedation (SP). From the most recent literature data show a use of SP in percentages ranging from 1% to 88%, for different care settings, and the SP duration at an average of 2.8 days. Dyspnea (35-50%) and hyperactive delirium (30-45%) are the most frequently reported symptoms such as refractory -

The study evaluated the percentage

were subjected to SP 21 patients (3,7%) for hyperactive delirium (53%), dyspnea (38%) and pain (9%), in analogy with international data. The way of administration used was predominantly subcutaneous routes of administration with continuous infusion.

Results: Were subjected to SP 21 patients (3,7%) for hyperactive delirium (53%), dyspnea (38%) and pain (9%), in analogy with international data. The way of administration used was predominantly subcutaneous routes of administration with continuous infusion.

Dyspnea (35-50 %) and hyperactive delirium (30-45%) are the most frequently reported symptoms such as refractory -

We believe that the lack of homogeneity of results compared to data reported in the literature about the percentage of patients receiving palliative sedation and the duration of palliative sedation is due to the non-uniqueness of definitions of palliative sedation, but it could also be the result of the need a more careful treatment of refractory symptoms before you call.

No source of funding

Abstract number: P117
Abstract type: Poster

Experiences, Beliefs and Practices of Health Carer Staff Associated with the Use of Advance Directives in Israel

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Background: Socio demographic and epidemiological change means that the process of modern dying is often
Community-based Care for Individuals with Rapidly Progressive Amyotrophic Lateral Sclerosis in the End-of-Life Period

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Purpose: Amyotrophic lateral sclerosis (ALS) usually causes death within 2-5 years after onset. It is said that the faster the disease progression is, the more difficult it is to support the patient. The purpose of this study was to elucidate how to provide care for patients with rapidly progressive ALS.

Method: Six ALS patients (4 males, 2 females; age range, 54-77) who had home care nursing and died within one year after discharge from hospital A were included. We collected data from medical records and conducted minimum structured interviews with their home care nurses and discharge liaison nurses. Qualitative-inductive analysis was used.

Results: Four of six patients used NPPV soon after diagnosis. Two patients, who died at home, were found dead in the morning by family members. The NPPV mask was displaced for one of those patients. The other patients died in the hospital from respiratory insufficiency, etc. Difficulties experienced by home care nurses included:
1) poor understanding of the disease by patients and families,
2) deterioration of family relationships,
3) care guidance for family caregivers, and
4) arrangements for home care support.

Discussion: Patients with rapidly progressive ALS and their family members had poor understanding about the disease. Collaboration between family physicians and hospital physicians is important for explaining the patient’s condition and prognosis. Early detection to reduce unexpected death caused by displacement of NPPV mask is important.

Conclusion: It is difficult to anticipate the prognosis of ALS patients. It is necessary to prepare for end-of-life care at the transition from hospital to home in order to support patients in living with a positive outlook.
**Aim:** Despite advances in cancer care, cancer related mortality is still significant. End-of-life care is thus an important aspect of cancer care. Available information on the use of medication can be helpful in assessing the quality of end-of-life care. This study assesses potentially inappropriate medication use in cancer patients during their last three days of life.

**Methods:** We firstly conducted an international survey among palliative care experts to assess the potentially (in)appropriateness of specific medication at the end of life. Secondly, a medical chart review of deceased cancer patients was performed to assess the extent to which the use of inappropriate medication differs between settings with an expected difference in quality of end-of-life care, using odds ratios.

**Results:** All experts rated supplements, bisphosphonates, replacement hormones, hyperuricemia and anticoagulants as probably inappropriate at the end of life. Nine medications were sensitive to distinguish different cancer care settings (see table).

**Conclusion:** This study shows medication use to differ per setting. Combining expert opinion and sensitivity analysis resulted in ten potentially inappropriate medications, which may be helpful in assessing quality of care at the end of life. Next step is to validate these potentially quality indicators.

<table>
<thead>
<tr>
<th>Likely inappropriate medication</th>
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<th>OR</th>
<th>OR</th>
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<tbody>
<tr>
<td></td>
<td>Hospital pre LCP implementation vs. hospice (ref)</td>
<td>Hospital LCP not used vs. LCP used (ref)</td>
<td></td>
</tr>
<tr>
<td>Replacements hormones</td>
<td>3.6</td>
<td>0.3*</td>
<td>7.3</td>
</tr>
<tr>
<td>Bisphosphonates</td>
<td>&gt;1.7§</td>
<td>1.8</td>
<td>-</td>
</tr>
<tr>
<td>Anticoagulants</td>
<td>1.2</td>
<td>0.9</td>
<td>4.2*</td>
</tr>
<tr>
<td>Antihypertensive</td>
<td>3.4</td>
<td>0.7</td>
<td>8.6*</td>
</tr>
<tr>
<td>Antiarrhythmic</td>
<td>2.8</td>
<td>1.3</td>
<td>0.5</td>
</tr>
<tr>
<td>Antiulcer drugs</td>
<td>3.5*</td>
<td>1.8</td>
<td>5.8*</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>3.1*</td>
<td>1.5</td>
<td>3.3</td>
</tr>
<tr>
<td>Steroids</td>
<td>0.9</td>
<td>1.9</td>
<td>1.4</td>
</tr>
<tr>
<td>Vasodilator drugs</td>
<td>4.9</td>
<td>3.8</td>
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[Odds ratios receiving likely inappropriate drugs]

LCP= Liverpool Care pathway for the Dying * p< 0.05 § Computation of OR not possible due to zero cases in cells. Zero was replaced by 1.
Aims: The purpose of current research is to explore the relationships between spiritual well-being and symptoms in advanced cancer patients. Also to know what is the role of spiritual well-being in the impacts that cancer-related symptoms have on quality of life, hopelessness and desire for hastened death.

Methods: This is a cross-sectional designed study, in which eighty five advanced cancer patients with mixed diagnoses have been recruited and were asked to fill out questionnaires of the Taiwanese version M. D. Anderson Symptom Inventory (MADSI-T), the Functional Assessment of Chronic Illness Therapy — Spiritual Well-being (FACT-Sp), the Beck Hopelessness Scale (BHS) and the Schedule of Attitudes Toward Hastened Death (SAHD). In the end, collected datas were analyzed with SPSS package.

Results: Spiritual well-being demonstrates a significant, negative correlation with symptom severity \( r = -0.46, p < .01 \) and symptom interfere \( r = -0.56, p < .01 \); symptom severity and symptom interfere are also both correlated with patients’ quality of life \( r = -0.54, p < .01, r = -0.64, p < .01 \), hopelessness \( r = 0.51, p < .01, r = 0.53, p < .01 \) and desire for hastened death \( r = 0.61, p < .01, r = 0.53, p < .01 \). Sleep problems are most annoying to advanced cancer patients. Also, patients with higher level of spiritual well-being have lower symptom severity (mean= 2.45) than patient with lower level (mean= 4.89). Further more, both patients’ desire for hastened death \( \beta = -0.40, p < .05 \) and quality of life \( \beta = 0.31, p < .05 \) demonstrate a significant prediction to spiritual well-being.

Conclusion: The current study results lead further understand to the relationships between spiritual well-being and cancer related symptoms. As a mediator and moderator, spiritual well-being can reduce the negative impacts caused by cancer symptoms.

Abstract number: P122
Abstract type: Poster

SPORT PC: The Impact of a Soccer Game on Physical and Emotional Symptoms in Advanced Cancer Patients: A Preliminary Report

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Aims: To determine the influence of watching an important soccer match on TV on physical and emotional symptoms and quality of life.

Methods: Mixed methods study. 25 advanced cancer patients divided in 2 groups : 20 watched the games (WG group) and 5 did not watch the games (controls). Assessments included the Edmonton System Assessment System (ESAS) and in the second phase 10 patients completed the Positive and Negative Affect Scale (PANAS) and a semistucture interview.

Results: During the game patients in the WG group experienced lower pain \( t=1.97; p=0.07 \) Vs \( t=1.77; p=0.17 \) for controls), anxiety \( t=-2.16; p=0.04 \) Vs \( t=0.71; p=0.54 \) for controls), and better sensation of wellbeing \( t=2.11; p=0.04 \) Vs \( t=0.73; p=0.51 \)for controls). PANAS results showed an increase in positive affect items (more interested, enthusiastic, inspired, attentive and active) and decrease in negative affect (less distressed, upset, guilty, hostile and irritable).

The qualitative analysis found that patients perceived game watching as a very positive event, capable of increasing the life meaning and improving physical (pain relief) and emotional wellbeing (satisfaction, distraction, enthusiasm, happiness, tranquility). Game watching was also perceived as promoting socialization, communication, and expression of feelings.

Conclusions: Our preliminary physical and emotional findings suggest that planning and conducting soccer game watching events can be considered as a non pharmacological symptomatic intervention as well as positive psychology for our patients and families who like soccer. More research is justified in the area.

Abstract number: P123
Abstract type: Poster

Media Representations of Euthanasia in Dutch Newspapers

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Objective: To investigate whether Dutch newspaper articles use the term ‘euthanasia’ according to the formal legal definition and to determine what arguments in favour and against euthanasia they contain.


Setting: The Netherlands, one of the few countries where euthanasia is legal.

Main outcome measures: Practices the term ‘euthanasia’ refers to; Arguments in favour of or against euthanasia.
Results: 307 articles contained the term ‘euthanasia’. Of these, 71 (23%) referred to practices outside the scope of the formal definition, mostly relating to the forgoing of life-prolonging treatments and the ending of life without a patient request. Of the articles with euthanasia as the main topic, 36% described euthanasia in the context of a terminally ill patient, 24% for elderly persons, 16% for persons with dementia, and 9% for persons with a psychiatric disorder. A wide range of arguments in favour of (n=14) and against (n=28) euthanasia were identified. Most frequently described arguments in favour of euthanasia were the importance of self-determination, and the fact that euthanasia alleviates suffering and contributes to a good death. Frequently mentioned arguments against euthanasia were the fact that suffering should be alleviated by better care, that the performance of euthanasia can be aggravating for a physician, that it is difficult to regulate, that society should protect the vulnerable, and that human life should be preserved.

Conclusions: Nearly a quarter of the newspaper articles use the term ‘euthanasia’ for practices that are outside the scope of the Euthanasia Law, potentially confusing the debate and leading to misunderstandings between citizens and physicians. Despite the formalisation of the legalisation of euthanasia in the Netherlands, the debate about its acceptability and boundaries is ongoing and both sides are clearly represented.

Abstract number: P124
Abstract type: Poster

Does the Type of Tumor and Place of Residence May Influence Place of Death of Terminally Ill Patients?

Hospital de Los Montalvos, Palliative Care Service, Salamanca, Spain

Objective: The aim of this study is to analyze the type of tumor and place of residence as factors that may influence place of death of cancer patients in the province of Salamanca.

Methods: We performed a retrospective cohort study of patients who died of cancer in the province of Salamanca, during the period from January 1, 1998 and December 31, 2007. Patients were collected from the database which were obtained from the Documentation Service Complex University of Salamanca and the National Statistical Institute of Spain (INE). Data collected include: leading cause of death, age, year of death, place of death, usual residence and sex.

Results: We collected a total of 10,347 patients who died of cancer in the province of Salamanca, during that period. Place of residence and sex: We analyzed a total of 9032 valid cases. Globally, there is a reason home deaths / hospital deaths, among patients from rural versus urban areas of 1.92 (95% CI 1.77 to 2.09). This ratio is 2.11, in males (95% CI, 1.89 to 2.36) and 1.56 in women (95% CI, 1.36 to 1.79). When analyzing the different tumors, we found statistical significance: The right home deaths / hospital is positive in pancreatic tumors 1.28 (95% CI 1.06 to 1.55), skin cancer 4.3 (95% CI 3.09 to 6.10) and CNS tumors 1.53 (95% CI 1.20 to 1.95), and negative in lung tumors 0.83 (95% CI 0.75 to 0.93), urinary 0.72 (95% CI 0.59 to 0.87), tumors of the ORL sphere 0.44 (95% CI 0.35 to 0.57), hematological 0.32 (95% CI 0.27 to 0.38) and liver and bile duct tumors 0.44 (95% CI 0.35 to 0.57).

Conclusions: The place of death of cancer patients depends largely on the health services available in your local area. Not surprisingly, contact with hospitals, favors the death in hospital. De Overall, lung tumors, urinary tract tumors, tumors of the ORL sphere, haematological and liver and bile duct tumors have a higher probability of dying in the hospital. This seems to be due to greater complexity in managing symptoms.

Abstract number: P125
Abstract type: Poster

Where Dying Patients with Terminal Illness who Are Admitted to the University Hospital in Salamanca?

Hospital de Los Montalvos, Palliative Care Service, Salamanca, Spain

Objective: The aim of this study is to analyze the place of death of cancer patients who are admitted to the university hospital in Salamanca in the province of Salamanca, during the period from January 1, 1998 and December 31, 2007.

Methods: To achieve this objective, an epidemiologic study, descriptive and ecological, of patients who died in the province of Salamanca during the period from January 1, 1998 and December 31, 2007. Data are from death certificates, and are processed by the National Statistics Institute (INE) and the database University Hospital of Salamanca. For the years 1998 we used the code of the International Classification of Diseases, Ninth Revision (ICD-9), and for the years 1999-2007 the equivalence of ICD-10. Were collected: cause of death, age, year of death and sex, and patients who died in hospital, the admitting service.

Results: Of the 10,347 patients dying from cancer in the province of Salamanca, died in hospital 5.868 (56.5%), of which 3.767 were male (59.16%) and 2.103 women (52.85%). For years, we see a steady increase of deaths in hospital with an increase of 18.59% between the 1998-2002 and 2003-2007, in males, and 13.69% in the same period, women. Service was studied where the death occurred had the patients dying from lung cancer, breast
or ovarian cancer, tend to die more often in the oncology department, patients with CNS tumors do in the care unit palliative hospital, patients with prostate cancer do so in the internal medicine, and patients with colorectal and gastric cancer die in the surgery department. When the results were analyzed by year of death was progressive increase in frequency to die in the hospital palliative care service.

**Conclusions:** It is found that age and the possibility of active treatment which increases the chances of dying in an oncology service. As you age, and therefore decrease the chances of treatment, this mortality is moved to the internal medicine and palliative care hospital.

**Abstract number:** P126  
**Abstract type:** Poster  
**The Palliative Home Care Teams Affect the Place of Death in Terminal Cancer Patients?**  

Hospital de Los Montalvos, Palliative Care Service, Salamanca, Spain

**Objective:** The aim of this study is to assess the influence of a palliative home care team on the place of death for terminally ill cancer patients.

**Methods:** We performed a retrospective cohort study of patients who died of cancer in the province of Salamanca, during the period from January 1, 1998 and December 31, 2007. Patients were collected from the database of home palliative care units in the province of Salamanca, from the Documentation Service Complex University of Salamanca and the National Statistical Institute of Spain (INE).

**Results:** A total 10,344 patients died from cancer in the province of Salamanca, which were followed by home-based palliative care team (HPCT) a total of 1724 patients. 5869 died in hospital (56.5%), of which 3,766 were male (59.16%) and 2,103 women (52.85%). Looking at the trend over time, we see a steady increase of deaths in hospital with an increase of 18.59% between the 1998-2002 and 2003-2007, in males, and 13.69% in the same period, among women. To analyze why home deaths/hospital, among patients followed and not followed by palliative home care units, it appears that the former have a higher ratio 3.62 (95% CI 3.24 to 4.05) of dying in home patients who do not have this track, overall, with a statistical significance of p< 0.001. There is a reason home deaths/hospital, among patients followed and not followed by HPCT, 9.26 higher (95% CI 7.95 to 10.80) in urban patients with home monitoring, and 2.5 higher (95% CI 2.01 to 3.10) for patients in rural areas followed by home care.

**Conclusions:** In our study shows that for every patient who dies at home, with no specific home care, die 3.6 patients who are receiving this attention, there are no sex differences. If we differentiate this assistance areas, in urban areas the percentage increases to 9.26 patients treated for a domiciliary care unit for every patient who does not receive this assistance.

**Abstract number:** P127  
**Abstract type:** Poster  
**Sex-based Disparities in End-of-Life Decision-making in Flanders, Belgium**

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**Background:** Sex is increasingly recognized as an important health determinant. Sex-related inequalities at the end of life however are largely under researched and unexplored.

**Aims:** To investigate in Flanders, Belgium whether there are (1) differences in demographic and/or clinical characteristics between male and female decedents; (2) differences between men and women in the prevalence of end-of-life decisions (ELDs) with a possible or certain life-shortening effect; (3) differences in decision-making about ELDs between men and women.

**Methods:** In 2007, we performed a post-mortem survey in Flanders, Belgium among physicians certifying a large representative sample (n=6927) of death certificates. Response rate was 58.4%.

**Results:** Women in general die at an older age than men (61.4% of women vs 41.1% of men older than 80). They more often die in a care home compared with men (31.4% vs 18.2%) who more often die at home (24.1% vs 17.9%). Men tend to die more often from cancer than women (45.4% vs 32.1%). Non-treatment decisions are more often made in women (28.0% vs 22.8%, p=0.003); euthanasia and alleviation of pain and symptoms with a possible or certain life-shortening effect (APS) are more often performed in men (3.6% vs 2.1% for euthanasia, p=0.023; 41.8% vs 36.9% for APS, p=0.012). These differences between men and women largely disappear after controlling for confounders, especially diagnosis and place of death. Bivariate associations were found between sex and decision-making with regard to the different ELDs. Some of these associations remained after controlling for confounders.
Conclusions: It is not the patient’s sex in itself that determines the likelihood of an ELD being made, but their different clinical profiles at the end of life. Although sex is not a determining factor in the prevalence of ELDs, it is an influencing factor in the decision-making process.

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Abstract number: P128
Abstract type: Poster

The Palliative Denominator in Cancer: The Epidemiology of Cancer Non-survivors

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Goals:
To 1; describe the epidemiology of cancer non-survivors, defined as the cohort of cancer patients who will not survive 5-years after the diagnosis, and 2; to employ this epidemiological knowledge to argue that the majority of the non-survivors are evident candidates for palliative care initiatives already at the time of the diagnosis.

Patients and methods: All incident cancer patients registered in 1993-2003 (N=24,162) from a 470,000 large population were followed individually from diagnosis to death or until 31 December 2008. Non-survivors were patients, who died less than 5 years after the diagnosis.

Main results: The cancer cohort’s 5 years survival was 41%, leaving 59% as non-survivors. The median survival of the 14,349 non-survivors was 0.6 year, and 78% died less than 2 years after the time of the cancer diagnosis (TOCD). The median age at TOCD was 72 years, 81% were older than 60 years, and 2% were younger than 40 years. The most frequent cancer types were lung cancer 21%, colorectal cancer 15%, prostate cancer 8% and breast cancer 7%.

Conclusions: Derived from this population-based cohort, it is estimated that 46% of all incident cancer patients can be placed in “a palliative care trajectory” already at the time of the diagnosis. The estimate is based on the assumption that patients with survival perspectives less than 2 years have advanced and/or disseminated disease at the TODC. Almost 1 in 3 of all incident cancer patients is presumed to be in obvious need of some kind of palliative care initiative at the time of the diagnosis, since he or she has a life span of less than 7 months. The study also shows that rehabilitation programs may be of relevance to around 22% of the non-survivors, since they have a survival perspective of more than 2 years.

Perspectives: This kind of epidemiological knowledge of non-surviving cancer patients is of importance in the planning and scaling of palliative care initiatives.

Abstract number: P129
Abstract type: Poster

End-of-Life Decisions and Continuous Deep Sedation until Death among Cancer Patients Compared to Non-cancer Patients in Flanders, Belgium

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Aims: Because of the high symptom burden and the specific disease course, patients with cancer and their physicians are more likely to face end-of-life decisions with possible life-shortening effects (ELDs). This study examines the incidence of ELDs and continuous deep sedation until death (CDS) in cancer patients compared to non-cancer patients in Flanders, Belgium.

Methods: A nationwide death certificate study was conducted. The physicians who attested the selected death certificates (n=6927) were sent a questionnaire.

Results: The response rate was 58.4%. Eighty six point one percent were non-sudden deaths of which one third was caused by cancer. Among the non-sudden death cases, intensified alleviation of pain and other symptoms (53.8% versus 31.7%, P< 0.001) and euthanasia/physician assisted suicide (6.8% versus 0.9%, P< 0.001) occurred more often in cancer patients, while there was no difference in non-treatment decisions and life-ending acts without patient’s explicit request. CDS occurred in one fifth of the patients in both groups. Competent cancer patients were less often involved in the ELD decision-making process than competent non-cancer patients (69.7% versus 83.5%, P=0.001). Ten point five percent of cancer patients made euthanasia requests compared to 2.1% of non-cancer patients (P< 0.001) and the requests were also more often granted.

Conclusion: The higher incidence of alleviation of pain/symptoms with possible life-shortening effect and of euthanasia/physician assisted suicide in cancer patients is likely related to a difference in disease trajectories and better access to end-of-life care. More research is needed to explain why cancer patients are less often involved in decision-making than non-cancer patients.
Access to Specialized Palliative Care Varied Strongly among Patients Dying from Cancer in Denmark

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**Background:** Ideally, the limited specialized palliative care (SPC) resources are allocated to those having the greatest needs. However, some international studies have shown unequal access to SPC (i.e. that other factors than need determine access).

**Objective:** To investigate whether differences exist in access to SPC among patients dying from cancer according to gender, age, diagnosis, and geographic region.

**Method:** The analyses were based on data from the Danish Palliative Care Database (DPD), a national quality of care database for SPC registering all patients referred to SPC in Denmark. The completeness of registration of patients in DPD is above 95%.

**Results:** Overall, 28.5% of Danish cancer patients who died in 2010 obtained access to SPC (4,240 out of approx. 14,858). Significant differences in access were found for gender, age, diagnosis, and geographic region (p< 0.05). The proportion of women dying from cancer who obtaining access to SPC was slightly higher than for men (29.2% vs. 27.8%). The access to SPC among patients with haematological malignancies was low (7.5%) whereas the access for patients dying from gynaecological cancers (37.6%), melanoma (52.7%), and pancreatic cancer (38.1%) was high. A large age gradient was found: half of those aged 40-49 years who died from cancer received SPC, gradually decreasing to 19% of the 80+. In the Capital and Southern Denmark Regions only 23.9% and 26.4% of those dying from cancer, respectively, received SPC compared to 31.1%-32.9% in the three other regions.

**Conclusion:** Access to SPC among patients dying from cancer varied strongly, and was lowest for those with haematological malignancies, the oldest, and those living in the Capital or Southern Denmark regions. It is unlikely that these disparities can be fully explained by differences in need.
Stroke is the third leading cause of death in Western countries. However, there is still a lack of research in the palliative care needs of stroke patients and their families. Unlike cancer, stroke is not immediately related to palliative care. Because of the difficulty of assessing a prognosis, the acute nature of stroke and the focus in hospitals on stabilizing the patient’s condition, the needs for palliative care are often neglected. Palliative care often comes up very late in the disease progress or not at all, although about 20% of Dutch stroke patients die in the first month after the stroke; (40% in the age group older than 85). Furthermore, those who survive a severe stroke have to live with serious disabilities. The aim of this study is to describe the decision-making dilemmas that relatives face in the acute phase of the stroke and to present a normative approach of how to deal with issues of palliative care in the acute phase after a stroke. In the first part of this research the experiences of relatives of stroke patients will be investigated. The methods used are open interviews with relatives (n = ±24) of patients who died after the stroke or who survived with severe disabilities. In the selection of respondents we strive for variety in different socio-biographical factors. In the interviews a narrative approach is used, in order to reconstruct the decisions that were taken in the acute phase. Interview data are qualitatively analyzed by focusing on the ethical dilemmas and values described by the respondents. The interviews with relatives are ongoing at the moment and the first results will be presented. Issues that will be addressed in the presentation are: how the patients’ autonomy is respected in the decision-making about whether or not to start with a palliative policy; shared decision-making in the acute phase; relatives’ views on communication with health professionals about end-of-life issues in the acute phase after the stroke.

Abstract number: P133
Abstract type: Poster

Researching Ethical Issues in Palliative Care: The Vignette Study Design

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Based on the 2001 WHO definition palliative care (PC) aims to improve the quality of life of patient and their families. With this aim questions of the individual organisation of treatment and the general access to PC provision arise. Therefore, beside clinical research improving evidence based practice, ethical issues need to be addressed, e.g. factors influencing decision making or attitudes of involved persons.

One underutilised methodological approach to explore these issues is the vignette study. It can be conducted qualitatively and quantitatively, in the latter case labelled as factorial survey. The data collection combines the key benefits of survey research with the benefits of experimental designs. Hypothetical situations or objects described in short stories (vignettes) need to be assessed by the respondents.

The factorial survey varies the standardised dimensions of the vignettes in an experimental design. Thereby the dimensions’ impact on the given judgements or the decisions made can be evaluated statistically.

Although the method does not measure performance in itself, it is able to identify effects of single influencing factors often mixed and biased in reality.

As an example of the realisation of the vignette study approach in PC research a study on values and attitudes of physicians related to decisions about withdrawing treatment for incompetent patients is presented. This study explores the value based a priori of German physicians who need to adhere to a new legislation for advanced directives since 2009. This legislation focuses much more on patient wishes then the previous law and affects the physician-patient-relationship as well as the role of legal guardians. Its purpose was to ensure more patient orientated treatment decisions and to disburden the involved physicians. At the same time, a recent guideline of the German Medical Association does not acknowledge the new legislation and thereby seeks to abate the intention of the Act.

Abstract number: P134
Abstract type: Poster

Ethical Issues in Palliative Care (PC) - A Qualitative Observational Study

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Background: Insecurities in dealing with ethical issues in PC often burdens patients, family members and staff. Thus, this study aims to identify, analyze and evaluate ethical issues in everyday practice of inpatient palliative care.

Methods: This qualitative study is based on an open, unsystematic participant observation at the PC unit of a German university hospital. During observation from March until April 2011 17 of the 22 inpatient patients were included in this study. Thereof 7 patients died during that period. The study population was completed by 22 members of the multi professional team.

The computer-based program MaxQDA was used for qualitative content analysis to identify, code and categorize ethical issues with their different facets in the data based on field notes. For objectification purposes the defined categories were reviewed by a second independent scientist.
Preliminary results: We observed 275 sequences and extracted 536 codings which consider ethical issues. These codings were grouped into 5 major categories: Treatment at the end of life (46%) including treatment decisions (82%) and pain and symptom management (18%); Communication (21%) with its minor categories truth telling (46%), (in)competency (44%), advanced directives (8%), taboos (3%) and confidentiality (2%); Patient’s autonomy (16%) including discrepancy of patient’s wish and well-being (61%), attitudes to treatment (21%) and wish for hastened death (17%); Care and nursing (15%) comprising family dilemmas (45%), dealing with difficult relatives (33%), nursing dilemmas (18%), differences in culture (3%) and spirituality (3%); Allocation of resources (3%) including monetary (70%) and non-monetary (29%) issues. Conclusion: This study helps to sensitize for circumstances with ethical relevance in PC. Thus specific guidelines can be derived to create more certainty for clinical everyday practice. As a consequence such a framework leads to an improved quality of patient care.

Abstract number: P135
Abstract type: Poster

The Good Neurologist: Obeying Surrogates or Caring for Families?

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Objective: As laid down by Dutch law, surrogate decision-makers ought to make medical treatment decisions in accordance with the assumed or previously expressed wishes of the incompetent patients they represent. How do neurologists actually involve these decision-makers in every day practice?

Methods: We performed 22 semi-structured interviews with neurologists from different Dutch hospitals with the question how they discuss potential treatment restrictions when seriously ill patients are admitted who cannot utter treatment wishes and give consent themselves. Analysing the data iteratively, our focus came to lie on the role which neurologists in these situations ascribe to the patients’ families.

Results: In general, the neurologists did not refer to family members as ‘surrogate decision-makers’. The relationship with families and other beloved acquaintances was seen as part of a complex patient care system. According to the neurologists, families gave essential information regarding patients’ wishes, but required help and care themselves, too. Providing this care regularly involved taking responsibility for - regularly far-reaching - treatment decisions, in the views of the neurologists in the best interest for both the physically suffering patient and his emotionally suffering family.

Conclusion: In daily practice, neurologists involve family members as information sources and at the same time as care receivers. The legal role of families as surrogate decision-makers is largely irrelevant. How should we deal with the friction arising from the two different normativities of law and practice?

Abstract number: P136
Abstract type: Poster

“I Don’t Want Last Time to Be the Last Time.” The Meaning of Sex in Life-limiting Illness

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Background: The literature describes sexuality as a holistic concept that is integral to each person throughout their lifetime. It influences how we perceive ourselves and is expressed through touch, roles and relationships. Palliative care claims to be holistic; yet sexuality is frequently overlooked in both research and clinical practice.

Research aim: To understand the meaning of sexuality for patients and partners of patients with life-limiting illnesses.

Method: In this Heideggerian phenomenological study, a purposive sampling strategy was used to recruit 27 patients and 14 partners of patients living with a life-limiting illness. Each person was interviewed twice and couples were interviewed separately. All interviews were audiorecorded and transcribed verbatim. Diekelmann and Ironside’s seven-stage analytical process was used to uncover shared meanings. This iterative process is fundamental to Heidegger’s hermeneutic circle of interpretation.

Findings: Sex is an aspect of sexuality that all participants described. Sex was considered a fundamental part of life that involved mutual enjoyment. It was also described as an obligation and signified failure, escape, or separation. The disease, treatment and healthcare interventions all impeded sexual connection between couples. Some people found alternative ways to connect while others became disconnected. Problems arose when the meaning that intimacy held for each partner within the coupled relationship diverged.

Conclusion: For many palliative care patients, sex is problematic or no longer feasible. How people manage this loss is affected by the meaning that sex holds for them and its significance for their coupled relationship. There is a role for professionals in providing people with opportunities to talk about this loss. Not all will want to speak of these
personal matters, but for those who do; palliative care professionals can facilitate communication between couples and support individuals in grieving their loss.

**Abstract number:** P137  
**Abstract type:** Poster  
**Impact of Palliative Sedation on Relatives of Dying Patients**  
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**Aims:** Palliative Sedation (PS) is a widely used practice to relieve unbearable suffering in dying patients when other measures are inefficient or intolerable. Relatives of patients receiving PS might have specific needs and worries that affect distress and satisfaction with PS. Assessing these factors could lead to a better understanding on what healthcare professionals can do to ease the experience of relatives of patients receiving PS.

**Methods:** We prospectively collected all cases of PS initiated during one year at the palliative care unit of a large university medical center and interviewed the relative identified as the primary confidant of the patient using a structured questionnaire. The questionnaire was developed on the basis of a similar study performed in Japan by Morita et al (J Pain Symptom Manage 2004).

**Results:** During the study period, 37 patients received PS. 2 had no relatives present during PS and 7 relatives refused to participate. The remaining 28 relatives could be interviewed with a mean time of 8 months between the patient’s death and the interview. 75% of the relatives (n = 21) were satisfied with PS, however 54% (n = 15) expressed a high level of emotional distress. 36% of the relatives (n=10) reported a lack of information on PS, which correlated with reduced satisfaction. 40% (n=11) were unprepared for changes in the condition of the patient and 57% (n=16) reported distress due to hindered communication with the patient during PS. Involving the patient in the decision-making process and feeling the timing was right for initiation of PS correlated with higher satisfaction and less distress. Ethical or legal concerns were not reported.

**Conclusions:** While the majority of relatives were satisfied with PS, a substantial number reported a high level of emotional distress. Relatives need early and comprehensive information on the procedure of PS and its effects on the patient, as well as emotional support during PS.

**Abstract number:** P138  
**Abstract type:** Poster  
**Trajectories of Family Caregiver Depressive Symptoms while Providing End-of-Life Care**  
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**Introduction:** Caregiver depressive symptoms may not be homogeneous. The purposes of this study were to identify individual trajectories of caregiver depressive symptoms and to profile the unique characteristics of individuals within a particular trajectory.

**Methods:** A longitudinal study using regression extension of latent class analysis was conducted on scores of the Center for Epidemiological Studies Depression Scale (CES-D) from 447 family caregivers whose relative died during the study period.

**Results:** Four distinct trajectories of caregiver depressive symptoms were identified and named as endurance, resilience, moderately symptomatic, and chronically distressed trajectory, contained 32.0%, 11.4%, 36.9%, and 19.7% of the sample, respectively. Family caregivers in the ‘endurance’ trajectory was comprised of relatively well-adjusted individuals with adequate financial support, ample psychological resources, stronger confidence in providing end-of-life care, and comparatively free of subjective caregiving burden. Family caregivers in the “resilience” trajectory had a weaker psychological resource and were more likely to be the patient’s spouse, have greater educational attainment and a financial status that could not make ends meet, and provide a higher intensity of assistance to a younger terminally ill relative than those in other groups. However, they experienced significantly less subjective caregiving burden. The strength of psychological resources was the only variable that differentiated moderately symptomatic trajectory from the “chronically distressed” trajectory.

**Conclusion:** Family caregivers of terminally ill cancer patients follow qualitatively distinctive depressive symptom trajectories. Priority for clinical interventions should be directed at interrupting the two unfavorable high depressive symptom trajectories and facilitating rapid return to healthy psychological functioning for family caregivers in the “resilience” trajectory.

**Abstract number:** P139  
**Abstract type:** Poster  
**Impact of Worry on Psycho-physical Symptoms. A Research Study on Family Caregivers of Cancer Patients**  
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**Background:** In family caregivers of cancer patients, involvement, stress and lack of coping abilities may lead
to psycho-physical disorders. Perseverative cognition, as manifested in worry, have a relevant role in anxiety disorders and somatic health. Aim of this study was to assess whether worry would act directly on psychological and physical diseases.

**Method:** Sample consisted of 107 family caregivers (77 female and 30 male). Participants completed twice a battery of self-report questionnaires (Caregiver Burden Inventory, Penn State Worry Questionnaire, Psychophysiological Questionnaire and Beck Depression Inventory).

Simple non parametric correlation (Spearman) was used to assess the statistical link between worry level and burden scores, somatic symptoms and measure of depression. One-way analyses of variance (ANOVA) were performed for comparisons of means between groups. Post-hoc tests (Bonferroni) were then used to determine which means differ. Simple linear regressions were employed to assess the capacity of worry measures to predict mental and physical health.

**Results:** A one-way ANOVA revealed statistically significant differences between worry measures and physical symptoms (F(2, 104)=17.09, p=0.000001). Probabilities for Bonferroni post-hoc test: low-worriers vs high-worriers p=0.00007, low-worriers vs worriers p=0.00005). Another one-way ANOVA revealed statistically significant differences between worry measures and level of depression (F(2, 104)=9.23, p=0.0002). Probabilities for Bonferroni post-hoc test: low-worriers vs high-worriers p=0.0017, low-worriers vs worriers p=0.009). A simple linear regression assessed the capacity of worry measures to predict the physical symptoms (β=0.67, p=0.001). Another simple linear regression assessed the capacity of worry measures to predict the level of depression (β=0.52, p=0.0001).

**Conclusions:** Worry is a crucial factor for mental and physical well-being of family caregivers, making more difficult the patients assistance.

**Study population:** Participants will be strategically selected, ethnic Nordic, able to give informed consent and participate in a group conversation. Patients must have cancer in the palliative phase and be ≥ 70 years old. Relatives must be ≥ 18 years old and hold different relations to the patient; spouse, children, grandchildren and siblings. The samples will consist of about 30 patients living at home, in addition to 1 - 3 next-of-kin, selected by the patient. The study seeks to explore gender differences in both groups and thus women and men will be recruited.

**Study methods:** The study incorporates both a qualitative and a quantitative approach. Hermeneutic philosophy will guide the qualitative approach. Data will be collected through family interviews, as to our knowledge not previously performed in Norway. The family model by Wright and Leahey (2009) and theory about focus group interviewing will be used. Quantitative data will be collected among relatives by means of two standardized measures.

**Results:** Because cancer affects both patient and family, we presume that family perspective represents a relevant approach to study relationships between cancer patients and their families. Family approach means seeing the family as a unit and at the same time acknowledge the individual family members. It is presumed that interviewing families will give different data about the units function than individual interviews. It will also give the opportunity to explore differences in perspectives and how family members influence, interact and motivate each other. Family perspective also gives the opportunity to study other relatives than the primary caregiver, which is necessary due to a so far, limited focus in palliative care.

**Abstract number:** P141
**Abstract type:** Poster
**Factors Associated with Caregiver Influencing Place of Death in Cancer Patients with Terminal Illness**

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**Objective:** The aim of this study is to analyze the factors associated with caregiver that may influence place of death of cancer patients served by a home palliative care team in the province of Salamanca.

**Methods:** We performed a retrospective cohort study of patients who died of cancer, during the period from January 1, 1998 and December 31, 2007. Patients were collected from the database of home palliative care units. Factors were included caregiver gender, relationship and age.

**Results:** Data on a total of 1724 caregivers, of which 228 were male (13%) and 1469 were women (85%), 27 were
Aims:
Ringerike Sykehus, Vestre Viken HF, Hønefoss, Norway
Mossin H.
Grounded Theory Study of Spouses Experiences Being Present in Hospital when the Patient Is Dying - A Poster
Abstract type: P142
Abstract number:

Conclusions: Patients whose sole caregiver is the spouse, are more likely to die in hospital compared with patients in whom the primary caregiver is her daughter. The effect are more likely to die in hospital compared with patients between 55 and 64.

65 and 74, to 3.28 (95% CI 1.88 to 5.72) for the period between 45 and 74 years. The reason deaths home/hospital is between 2.75 (95% CI 1.11 to 6.80) in the period between 65 and 74, to 3.28 (95% CI 1.88 to 5.72) for the period between 55 and 64.

Conclusions: Patients whose sole caregiver is the spouse, are more likely to die in hospital compared with patients in whom the primary caregiver is her daughter. The effect of social support network of patients reflects the active involvement of family care at the end of life.

Abstract number: P142
Abstract type: Poster
Being Present in Hospital when the Patient Is Dying - A Grounded Theory Study of Spouses Experiences

Mossin H.
Ringerike Sykehus, Vestre Viken HF, Hønefoss, Norway

Aims: Although 50 % of cancer patients in Norway die in a hospital setting, there has been little research exploring how family members experience their presence at the hospital during their loved ones last days before death. This study aimed to gain an in-depth understanding of these experiences, and to advance knowledge for improving palliative care in relation to caregivers.

Method: A grounded theory design was used, with data derived by interviews with 8 female spouses.

Results: The data revealed a core category defined as Maintaining presence - for the other and for one’s own sake, embracing four categories - to find one’s place, to know, to support each other and to terminate. The core category represents the couple’s need to keep continuity in the relationship, physically and emotionally, even when the patient is admitted to hospital.

Conclusions: This study displays the importance that health care workers acknowledge and organize for family members to be able to spend time or cohabit with patients admitted to hospitals at the terminal stage. This may increase family members’ sense of empowerment and coping, and positively influence how they experience the period both before and after the death of their loved ones.

Abstract number: P143
Abstract type: Poster
Spouse’s Experiences and Needs as Supporters of People with Dementia at the End of Life in Nursing Homes in the United Kingdom: An In-depth Longitudinal Pilot Study
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Aim: Nursing homes provide care for significant proportions of people with dementia . The experiences and needs of close family members are not well understood. This study aimed to elicit and critically examine accounts of ‘spouse carers’ of people with advanced dementia in nursing homes.

Methods: Spouse carers (n=10) were recruited from two nursing homes in Northern England. Participants were interviewed individually on three occasions over a six month period. They were also asked to keep a diary, at least weekly for four weeks. A ‘thumbnail’ profile of each participant was written and content analysis performed.

Results: Seven women and three men, whose spouse (aged 66-97) was living in a nursing home, were interviewed.

Three major needs of spouse carers were identified. These concerned the emotional demands of caring, the transitions of care giving and dealing with uncertainty. That uncertainty is largely due to difficulties with prognostication for people with dementia. Spouse carers also had their own health support needs, but caring for self tended to carry feelings of guilt.

Uncertainty faced by carers has been described previously. Lack of specific support for this group of spouse carers is a new finding. Some participants had joined general carers’ support groups, but the majority of members were bereaved carers. Whilst aspects of support group membership could be helpful, there were potential difficulties. Problems could be shared and potentially eased within support groups, but the ‘burdens’ of all group members had to be heard and ‘carried’. The amount and content of conversations with friends was considered very carefully, for fear of losing friendships.

Conclusions: Spouse carers of people with dementia are an important and growing group whose unique needs have not been recognised or addressed. This group of carers found current systems of support to be inadequate. Further research is needed to develop and test appropriate interventions.
Caregiver’s Willingness in Communicating Diagnosis and Prognosis to Patients in Palliative Care

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Objective: Different social norms influence the type and amount of information provided to palliative care patients. Aims of our study were to assess, in three Italian Palliative Care Units, caregivers’ knowledge about patient’s diagnosis and prognosis and willingness to inform their loved one and to evaluate possible differences between caregivers of patients with and without cancer. Moreover the psychological and everyday burden was considered.

Method: 250 caregivers of palliative care in-patients (90% with cancer and 10% without cancer) participated to the study and were interviewed by senior psychologists.

Results: Mostly all caregivers knew their loved diagnosis and prognosis (240/10); 51% among the caregivers of cancer pts vs 28% caregivers of non cancer pts were against communication about diagnosis and prognosis (p=0.3) independently of patients knowledge. For 19% the issue was not pertinent due to severe clinical conditions. Patients with cancer less frequently knew their diagnosis (45% vs 60%; ns) and prognosis (38% vs 67%; p=.03) compared to patients with a non-cancer diagnosis. When the prognosis was fatal within estimated three months (91%), mostly all caregivers knew it but almost none was favorable to communication (99%).

Main caregivers’ burden emerged in the following area: modification (perturbation?) of family routine (74%), leisure time (62%) and work/domestic activities (47%); consequences on psychological wellbeing (52%). No differences emerged between cancer and non cancer patients.

Conclusions: In the Italian context, what to tell or not to tell in palliative care is still controversial. Often caregivers, heavily distressed by taking care, tend also to carry the patient’s burden by taking them in the dark. Communication must always stem from a tailored intervention in order to help the patient to approach death with tolerable knowledge and dignity and to support the caregivers.

Voluntary Work Organization in Palliative and Hospice Care in Poland as Seen by Hospice Employees

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Background: The operations of palliative and hospice care institutions in Poland are based on both paid work of the staff they employ and provision of services by volunteers working on a voluntary basis, without any remuneration.

Aim: The paper is aimed at examining the perception of voluntary work in the framework of the organizational structure of a palliative care institution by its employees.

Methods: The diagnostic survey method was used. The research tool was an anonymous questionnaire addressed to people who render paid services in Polish hospices.

Results: The study involved 213 employees from 29 palliative and hospice care institutions in Poland, where volunteers provide their services. The majority of them (74%) co-operated with volunteers in the provision of patient care. The employees enumerated the activities that should be performed by volunteers, and they include in particular: accompanying patients (94%), organizing public collections and charity campaigns (68%). According to a half of the respondents, all the tasks performed in a hospice by volunteers can be performed by employees, whereas a little under 1/5 say that the scope of volunteers’ tasks differs from that of the employees. 87% of the employees think that the assistance offered by volunteers in a hospice leads to an improvement of the patients’ quality of life, while according to 66%, the hospice employees benefit from it, too, as volunteers indicate them significant problems concerning patients.

Conclusion: Volunteers in palliative and hospice care institutions in Poland co-operate with their employees, especially in the area of patient care. Nevertheless, they should also become involved in tasks beyond the scope of such care, such as public collections and charity campaigns. The view according to which employees could perform volunteers’ tasks in full does not mean that they actually fulfill these tasks.
Aims: To describe psychosocial stress and emotion regulation among family carers of individuals enrolling in oncology phase 1 clinical trials.

Methods: One-time survey assessing family carer psychological status and distress, health status, emotion regulation and adaptive resources.

Results: 52 family carers (mean age 57.3 y, SD 11.4; 57% female) responded. Most (83%) were spouses, lived with the patient (96%) and spent 50 or more hours / week caregiving (84%). Respondents had moderate perceived stress (Perceived Stress Scale (PSS) mean 24.1, SD 8.6) and anxiety (State-Trait Anxiety Inventory (STAI) mean 39.1, SD 10.8). 40% exceeded Center for Epidemiologic Studies-Depression Scale (CESD) depression threshold (≥16). Carers reported higher positive (mean 34.3, SD 6.9) than negative affect (mean 21.7, SD 7.1) (Positive and Negative Affect Scale-PANAS). Caregiver Reaction Assessment (CRA) scores indicated moderate distress. 67% rated their health as excellent or very good; 12% as fair or poor. SF-36 scores were higher than population norms (means 54.5 - 79.4; SD 18.8 - 46.4). Respondents had neutral Emotion Regulation Questionnaire (ERQ) scores (3.6 - 4.9). Difficulties in Emotion Regulation Scale (DERS) scores indicated moderate difficulties (total mean 70.7, SD 16.0). Carers identified positive aspects of caregiving (Benefit Finding Scale (BFS) mean 3.8, SD 0.7; Positive Aspects of Caregiving (PAC) mean 35.8, SD 7.4;) and had preserved social support (ENRICHed Social Support Inventory (ESSI) mean 33.2, SD 6.5). Brief COPE Inventory scores were highest for Acceptance (mean 6.7, SD 1.3) and Use of Emotional Support (mean 6.0, SD 1.6) and lowest for Behavioral Disengagement (mean 2.4, SD 0.9) and Denial (mean 2.8, SD 1.3).

Conclusions: Family carers of persons enrolling in phase 1 trials reported wide variation in positive and negative responses and difficulties with emotion regulation, indicating a need for assessment and interventions to improve family carer outcomes.
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Research aims: The purpose of this study was to evaluate the Living with Hope Program (LWHP) by testing the authors’ Living with Hope (LWH) conceptual model in which self-efficacy and loss and grief were hypothesized as intervening variables for changes in hope among rural women caring for persons with advanced cancer. Sample: Thirty-six rural women from rural areas in 2 western Canadian provinces consented to participate. The majority were wives/spouses [30 (87.5%)] with a mean age 59.6 (SD 11.7) and had been caregiving on average for 30. 16 months (SD 30.17).

Study design/methods: Using a time-series mixed method embedded design (QUANT+qual), baseline measures of hope (Herth Hope Index), self-efficacy (General Self-Efficacy Scale), and loss/grief (Non-Death Revised Grief Inventory) were collected from the subjects. All subjects received the LWHP which involved seeing a Living with Hope Film and then working on a hope exercise entitled "Stories of the Present" for two weeks. Qualitative data was collected from the directed journaling exercise to inform the quantitative data. Subjects were post tested on the variables at Day 7 and Day 14. Data Analysis: Generalized Estimating Equations (GEE) was used to test the model over time. All journals were transcribed and analyzed using narrative analysis.

Results: At all three time points, self efficacy (p=.00) and grief and loss (p=.00) were significant factors associated with hope. After adjusting for self-efficacy and grief/loss there were no significant changes in hope from baseline to day 7 or baseline to day 14. Qualitative data suggests that writing in the journals was helpful in fostering hope within the context of the chaos of caregiving.

Conclusion: Further development and evaluation of the LHWP is recommended with larger sample sizes.

Source of funding: Canadian Institutes of Health Research Operating Grant

Abstract number: P149
Abstract type: Poster

Construction of a Screening Tool for Family Complexity in an Acute Palliative Care Unit

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Background: Acute Palliative Care Units (APCU) are busy and demanding places. Early and best identifying complex situations could allow best chances of appropriate care.

Aim: To build up a screening tool for family complexity, allowing prioritization of social work intervention in APCU.

Study population: Main carers (MC) of advanced cancer APCU in-patients

Design & methods: A purposely designed questionnaire with 17 questions on 9 domains: Patient; Family structure; Housing; Caring capacity; Use of resources; Economy; Giving up and Perspective. MC of consecutively admitted patients were screened within 48 h after admission, scoring from 0-80 points. A standardized mean time was allocated for 12 predefined social work interventions; the sum of the Time Expended by the Social Worker (TESW) during admission was assumed as expression of complexity and was used as the dependent variable. Sample size was estimated to be 100 MC. Study protocol was approved by the Ethics Committee.

Statistics: Apart from descriptive analyses, a linear regression was carried out to identify the most explicative variables; and analysing median TESW and the score obtained, the best logistic regression model was searched to classify two family groups (mild and high complexity) using the ROC Curve.

Results: Of 100 screened MC, 80 were women (mean age 58), 65 spouses. Forward selection in the Linear regression identified 3 explicative variables: 1- MC have to take care of other dependent persons; 2-MC had availability during previous admissions and 3-MC is in the mood of caring the patient in the future. Mean length of stay was 10.2 days (mortality 38%), mean number of interventions/patient 3.7 and median TESW 140 minutes. A cut-off score of 28 was selected, with a sensibility of 78.4% and specificity of 49% in identifying the two family groups.

Conclusions: A screening tool was successfully built-up for family complexity screening in an APCU. It is currently in the process of validation.

Abstract number: P150
Abstract type: Poster

Attitudes of Dutch Nurses towards their Involvement in End-of-Life Decisions with a Possible Life-Shortening Effect

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Background: Nurses are often involved in end-of-life decision making as they play an important role in caring for terminally ill patients.

Aim: To investigate nurses’ attitudes towards their involvement in end-of-life decisions with a possible life-shortening effect, and a possible relationship with socio-demographic characteristics and work-related factors.

Methods: A representative sample of 903 nurses in the Netherlands received a written structured questionnaire about experiences with medical end-of-life decisions, and the extent to which they agreed with statements about attitudes towards and their role in medical end-of-life decisions on a 5-point scale. Logistic regression models were fitted for each statement to determine the relation between nurses’ attitudes and socio-demographic and work-related characteristics.

Results: The response rate was 66 percent. Most nurses, especially highly educated nurses, nurses working in a hospital, and nurses who had experience with or had received training on end-of-life decisions, agreed that patients talk rather to a nurse about end-of-life decisions than to a physician (64%). In particular highly educated and female nurses, believed that they are in a better position to assess patients’ wishes than physicians are (38%). Most nurses, especially those working in a hospital and nursing home agreed that they should be involved in the whole process of end-of-life decisions (74%), and in decisions to withhold or withdraw life sustaining treatment (58%). Though the core value of nursing is the patient’s well-being most nurses believed that nursing may also include decisions with a possible life shortening (71%).

Conclusion: Overall, nurses agree that decisions with a possible life-shortening effect are part of their job and they want to be involved in these decisions. Work setting seems to be the most important determinant regarding the preferred involvement in decisions which may have a shortening effect.

Abstract number: P152
Abstract type: Poster

What Do We Learn if We Train Former Carers to Interview Other Carers about their Needs? Findings from a Qualitative Service User Involvement Study in Palliative Care

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Accurate needs assessments are critical in facilitating the provision of appropriate services. Likewise, service user involvement is a key policy and practice driver. In this study, we harnessed energies around user involvement to recruit former carers to conduct needs assessment interviews with current carers. The aim was to identify what needs would be discussed if it was carers, rather than researchers, conducting interviews.

Former carers were trained to conduct qualitative research interviews with carers of people receiving palliative services. Ten interviews were conducted. Thematic analysis enabled the exploration of what was said, focusing on the identification of key unmet needs. Conversation analysis was then applied to examine in detail how accounts and identities were constructed, and to determine how interviewer and interviewees’ shared experiential backgrounds shaped the style and content of the discussion. NHS ethical approval was granted for the study.

Extensive training was required covering both the pragmatic and technical elements of research interviews. After training, former carers were able to elicit informative accounts of unmet needs from current carers. Conversation analysis identified how interviewer and interviewee accomplish the complex task of managing what is assumed as ‘given’ knowledge and what is ‘new’ to another carer. By dissecting the speech acts within interviews, we have a better understanding of how carers construct their identities, and their needs in end-of-life care.

The study enhances understandings of service user involvement, and has developed important insights into carers unmet needs. The data also show how carers’ identities are formulated in palliative care. Since this was a cross-sectional study we cannot claim that carers elicit ‘better’ information than career researchers, but the data does establish how carer accounts are constructed and that this method has potential for future needs assessment and research.

Abstract number: P153
Abstract type: Poster

Sharing Everyday Life with a Person who Has Eating Difficulties at the End of Life

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Background: Dying persons often have eating difficulties. Their partners may experience responsibility for the person’s nutrition intake. Adequate nutrition intake is important for physical wellbeing, but food preferences, food rituals and eating habits, all imbedded in everyday life, are also significant to quality of life. Previous literature mainly focus on relatives’ experiences of practical matters related to artificial nutrition support, rather than the meaning to shared everyday life.
**Aim:** To get enhanced understanding about partners’ experiences of sharing everyday life with a dying person who has eating difficulties.

**Method:** Interviews performed with 9 partners, recruited from an advanced palliative home care unit in Sweden, 3-6 months after the death of their partners. Data were analyzed with interpretive description.

**Results:** Situations around mealtimes and food/nutrition support meant active participation and challenges. This was described as a struggle to maintain ordinary everyday life. Success or failure to make the dying person eat or receive nutrition support was described as a negotiation process; each bite or milliliter being a marker for hastening or postponing death. Artificial nutrition support brought about feelings of security; assuring the dying person’s continuous existence, and assuring recurrent communication with the home care team. The participants had positive experiences of being care givers, but they also expressed feelings of powerlessness. In everyday life they described being able to find good and joyful moments, but they also described feelings of unfamiliarity towards their dying partners, mainly related to changes in food preferences and eating habits.

**Conclusion:** The findings illustrate the complexity in sharing everyday life with a dying person who has eating difficulties. Mutual and open dialogue about issues around nutrition intake may have profound impact on partners’ capacity to handle everyday life with a dying person.

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**Abstract number:** P154  
**Abstract type:** Poster  
**PICC Line versus Port Line: An Observational Study to Compare Quality of Life of Patients with Two Different CVC Types**

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**Introduction:** Patients with chronic diseases, especially those affected with cancer, often need medium/long-term infusional treatments. The therapeutic approach consists of a medium/long-term central venous catheter (CVC) implant. The most common CVC types of catheters are Port and PICC (Peripherally Inserted Central Catheter). It is fundamental to evaluate the quality of life of patients, especially of those in critical area.

**Objective:** Evaluate and comparing the quality of life and the psychological distress of the patients after implant of the two different CVC (PICC vs Port).

**Study design:** The study provides an evaluation at base line and a follow-up at 1 and 3 months after implant.

**Materials and Methods** A sample of 122 patients: 70 with PICC and 52 with PORT.QL-INDEX DI SPITZER and KARNOFSKY PERFORMANCE STATUS were employed to evaluate the quality of life of patients. Distress was evaluated through ESAS scale e del GHQ-12. After the evaluation at baseline the questionnaires were given after 1 month and 3 month hereafter.

**Results:** Patients with PICC are older than those with Port (69.8 vs 60.1 p< .001). At baseline patients with PICC show a global worse quality of life (p<.05) and also worse scores according to “feelings”(p<.05), “activities” (p<.05) and “daily life”(p< .05) (QL- Index di Spitzer). After the implant there is an improvement in the quality of life for both categories of patients. PICC patients at baseline show a lower score in reference to Karnofsky Performance Status activity index (66% vs 74% p< .05). After implant the activity index shows an increase but no significant differences are presented between the groups. No significant difference are presented according to distress.

**Discussion:** Considering that patients with PICC at baseline show a higher disability scale and a worse quality of life, the no-significant differences evaluated at follows-up let us hypothesize that patients with PICC may have an improvement better than those with Port.

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**Abstract number:** P155  
**Abstract type:** Poster  
**Advanced Cancer Patients’ Self-assessed Physical and Emotional Problems on Admission and on Discharge from Hospital General Wards - A Questionnaire Study**

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**Aim:** Most cancer patients receiving palliative or life-prolonging treatment are not in specialist palliative care and little is known about their problem profile. We aimed to describe the incidence of advanced cancer patient-reported physical and emotional problems on admission and discharge from general hospital wards and the health professionals’ reported intervention.

**Methods:** Patients hospitalised with advanced cancer, at seven hospital departments, completed the European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire, EORTC QLQ- C15-PAL on admission and discharge. The absolute scores 1-4 were transformed to a linear scale from 0-100. The incidences of the problems areas and the scores were dichotomised in intensity categories; ‘00-33.9’ (questionnaire response categories ‘1’ and ‘2’) and ‘34 -100’ (response categories ‘3’ and ‘4’). Changes in patients’ intensity scores were tested using the Wilcoxon
signed rank test. Health professionals’ reported interventions were extracted from retrospective journal reading.

**Results:** Patients completed the questionnaire on admission (n=97) and discharge (n=46). The average number of problems in the intensity category ‘34-100’ on admission was 5 (SD 2) and on discharge 4 (SD 2). The test showed significant change in mean score for six out of nine problem areas in the intensity category ‘34-100’, but generally 67-70% of the patients remained in the intensity category. The highest concurrence between patient-reported problems (response category ‘3’ or ‘4’) and reported intervention from health professionals was related to physical function, pain, constipation and loss of appetite.

**Conclusion:** Palliative cancer patients’ self-reported problems on admission and discharge from hospital indicate a need for further focus on potential improvements in palliative services on general wards, and a specialised service with focus on physical function, pain, constipation and loss of appetite.

**Abstract number:** P156

**Abstract type:** Poster

**Utilising Hospital Administrative Datasets to Identify Patterns of Service Use in Patients with a Primary Malignant Glioma**

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**Aims:** The supportive and palliative care needs of patients with primary malignant glioma (PMG) are not well understood despite patients having a high burden of symptoms, psychosocial distress and care. The aim of this study was to examine current patterns of hospital use to provide a basis for planning appropriate care.

**Methods:** The Admitted Episodes Dataset, Emergency Dataset and Death Index are linked allowing patient care to be tracked over time and across sites of care. All patients admitted to hospital between 1 July 1999 and June 2009 with an incident diagnosis of PMG were included. Variables of interest were analysed using descriptive statistics and logistic regression analysis.

**Results:** We identified 1,997 patients meeting the inclusion criteria, of whom 58.7% (n=1173) died during the follow-up period. Over the course of their illness, they had a mean of 4.9 hospital admissions, a mean stay of 49 bed days and a mean of 2.6 emergency presentations. Of those who died with more than 4 months of follow-up (n=680, 34%), factors significantly related to high utilisation (>31 bed days) in the last 90 days of life included: symptoms of intracranial pressure in the preceding 90 days (OR 3.6, 95% CI:1.3-9.9); initial diagnosis within a non-teaching hospital (OR 2.8, 95% CI: 1.7-4.7); being within a higher education and professional occupation decile (OR 1.1, 95% CI: 1.0-1.2) and higher use of supportive care from diagnosis to 90 days prior to death (OR 2.4, 95% CI:1.8-3.2). Use of palliative care from diagnosis to 90 days prior to death was not found to have a significant relationship (OR 1.0, 95% CI: 0.6-1.8, p=0.9).

**Conclusion:** We identified several factors relating to high utilisation of acute care at the end of life. The ability to link non-identifiable patient data across hospitals in Victoria gives valuable insights into service use of patients with PMG to enable supportive and palliative care systems to develop appropriate responses.

**Abstract number:** P157

**Abstract type:** Poster

**Understanding the Supportive and Palliative Care Needs of People with Primary Malignant Glioma and their Carers**

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**Aims:** People with primary malignant glioma (PMG) have distinct supportive and palliative care needs which are poorly understood and managed. The aim of this qualitative study was to explore the needs of patients with PMG and their carers to inform the development of an improved model of care.

**Methods:** Consecutive patients and carers were approached through neurosurgery, oncology and palliative care units of two metropolitan hospitals. Bereaved carers were identified by health care professionals (HCPs) and invited by letter to participate. Semi-structured interviews were conducted until data saturation. HCPs from two metropolitan hospitals and one community palliative care service participated in multidisciplinary focus groups. Interviews and focus groups
were recorded, transcribed and thematically analysed by 3 independent researchers. All investigators reviewed the interviews for consistency and cross validation.

**Results:** Interviews were held with 8 patients, 8 carers, 8 bereaved carers, and 6 focus groups involving 35 HCPs (13 nurses, 11 doctors and 11 allied health clinicians; mean 17 years practice). Carers reported difficulty managing subtle behavioural and personality changes, cognitive decline and poor insight, which were often unrecognised by HCPs. Patients described difficulty accessing and navigating complex care services which were often unresponsive. Carers had information needs that sometimes conflicted with patients’ needs for hope. HCPs reported difficulty in planning care as functional status commonly fluctuated, resulting in offers of support being reactive when patients expressed need or marked disability rather than offered routinely.

**Conclusions:** Coordination of care through an identifiable, accessible and informed HCP appears critical. This would ensure service and information provision appropriate to disease state, assist navigation through health services and ensure palliative care services are better integrated into patient and family care.

**Abstract number:** P158
**Abstract type:** Poster

**To Be or Not to Be? Primary Thromboprophylaxis in People with Advanced Cancer: Views of Oncologists and Palliative Physicians**


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**Aims:** Prevention of venous thromboembolism (VTE) through the use of a risk assessment tool (RAT) and delivery of primary thromboprophylaxis (PTP) to hospital in-patients is a UK priority. A proportion of UK hospital income is dependant on compliance with the national VTE prevention strategy. For palliative care, guidelines agree PTP is inappropriate in the dying, but to be considered if there is reversible pathology. We aim to present the views of oncologists and palliative physicians about this issue.

**Methods:** This qualitative study was designed to explore what influences doctors’ decisions about diagnosis and management of VTE. Interviews were conducted with 45 doctors (range of grades of oncologists, palliative physicians and GPs) in Yorkshire, England and South Wales.

**Results:** The initial topic guide did not include a question about PTP, but it arose as a strong theme, although not from GP interviews. In hospital, oncologists described the vast effort invested in RA due to the centrally imposed national drive; seen as beneficial by some. However, senior oncologists expressed concerns about the implementation of a RAT which could lead to inappropriate PTP over-prescription. They felt: i) the RAT was implicitly weighted towards prescribing PTP, and, ii) although the financial driver is RA, not PTP prescription, this may be misinterpreted by junior staff making day-to-day decisions. Palliative physicians had divergent views about PTP in hospices (which are not subject to National RA targets). Some routinely stopped all PTP but others had implemented RA with a modified RAT. A concern was expressed that some hospice patients might not receive appropriate PTP.

**Conclusions:** Hospital and hospice PTP practice span a spectrum risking inappropriate management at each extreme. This data raises a concern that PTP may rest on the basis of place of admission rather than clinical need. An evidence gap regarding PTP in people with advanced cancer is highlighted.

**Abstract number:** P158

**Abstract type:** Poster

**Extent of Palliative Care Need in the Acute Hospital Setting: A Prospective Survey of Two Acute Hospitals in the UK**


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**Background:** The UK End of Life Care Strategy has highlighted the delivery of high quality palliative care in acute hospitals as an area of priority. The identification of patients who may benefit from palliative care is recognised as problematic globally, and health professionals have reported difficulties with recognising when a palliative care approach may be appropriate.

**Aim:** To explore the extent of palliative care need in the acute hospital setting, and to explore agreement between different sources in the identification of patients with palliative care need.

**Method:** A prospective survey of in-patients at two UK acute hospitals. Hospital case notes were examined for
Abstract number: P160
Abstract type: Poster

Exploring Health Professionals’ Views Regarding the Optimum Physical Environment for Palliative and End of Life Care in the Acute Hospital Setting: A Qualitative Study

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Background: Limited evidence exists relating to key elements of the optimum physical hospital environment for patients receiving palliative and end of life care in acute hospitals. The aim of this study was to explore the perspectives of health professionals in the UK regarding the optimum physical environment for palliative and end of life care in the acute hospital setting.

Methods: Qualitative focus group study with 24 health professionals from an acute hospital, a community hospital, and a hospice in the UK.

Findings: Participants agreed that provision of appropriate privacy options was key to achieving an optimum physical environment. However, there was little consensus as to whether single room accommodation, or multi-bed accommodation was most appropriate. A comfortable and homely environment is important, but difficult to achieve in a clinically focussed environment. The hospital environment may also be suboptimal for staff provision of care. The environmental needs of families should be considered alongside the needs of patients.

Conclusion: The results reveal that according to the GSF prognostic guide, over a third of hospital in-patients meet criteria for palliative care need. Consensus between medical staff, nursing staff and the GSF was poor regarding the identification of patients with palliative care needs. This has significant implications for patient care and for the management and organisation of palliative care in the hospital setting. These results have implications both in the UK and internationally, as international policy seeks to drive up quality of care for the increasing numbers of patients with palliative care needs receiving care in the acute hospital setting.

Abstract number: P161
Abstract type: Poster

The Danish Palliative Care Trial (DanPaCT) Protocol: Preliminary Results and Subsequent Protocol Revisions


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Background: Patients with advanced cancer not referred to specialised palliative care (SPC) have a significant prevalence of symptoms, problems, and needs. The Danish Palliative Care Trial (DanPaCT trial) investigates whether patients with metastatic cancer, who report palliative needs in a screening, will benefit from being referred to SPC.

Aims: To investigate the feasibility of the DanPaCT protocol.
Method: The trial is a randomised, multicentre clinical trial conducted in six Danish SPC centres. The planned sample size is 300 patients. Consecutive patients from departments of oncology were screened with two questionnaires (EORTC QLQ-C30 and Three-Levels-of-Needs Questionnaire (3LNQ)) if they:

- a) had metastatic cancer;
- b) were 18 years or above; and
- c) had no contact with SPC.

Patients were eligible for the trial if they had

1) at least two palliative needs (assessed by combining responses to EORTC QLQ-C30 and 3LNQ) and
2) at least three additional symptoms (assessed with EORTC QLQ-C30). Patients were randomised to SPC plus standard treatment versus standard treatment.

Results: During the first two months (four centres recruiting), 237 patients were eligible for screening. Of these 200 (84%) received the questionnaire, and 167 (84%) completed it. Of these, only 14 (8% of those completing the questionnaire and 6% of the target group) were eligible for the trial. As the trial would recruit a too narrowly selected sample and because it was not feasible, inclusion criteria were changed by removing the 3LNQ. New criteria are 1) one palliative need (assessed with EORTC QLQ-C30) and 2) at least four additional symptoms (assessed with EORTC QLQ-C30). With these criteria, about 48% of patients screened are eligible for the trial.

Conclusion: The modified DanPaCT protocol is feasible and will evaluate the effect of early SPC in advanced cancer patients with palliative needs. Clinicaltrials.gov (NCT01348048).

Abstract number: P162
Abstract type: Poster

Quality of Care of Cancer Patients in Israel
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Background: Every year, some 12,000 people die of cancer in Israel. Although awareness of the need for palliative care has been growing, only a small minority receive it. In order to demonstrate the advantages of palliative care to decision-makers and service providers, we conducted a study to examine the quality and cost of treatment for patients who received/did not receive home-hospice care. This presentation will show the differences in the cost of care between home-hospice patients (HHPs) and non-home-hospice patients (NHHPs).

Study design: An analysis of administrative data on all deceased patients with metastasized cancer in one district of an Israeli HMO during the first 8 months of 2009.

Results: HHPs constituted only 15% of the study population. The average cost of care per patient in the last 6 months of life was 63,586 NIS (about 12,500 Euro) and the average cost of care per patient in the last 2 months of life was NIS 25,522, i.e., 47% of the total average cost in the last 6 months. Some 68% of the expenses of the last 6 months were incurred for acute hospitalization and the remainder - for community care, home-hospice, medication, treatments in day-hospital and nursing homes. In the last 6 months of life the average cost of care for HHPs was 26% lower than for NHHPs, and 42% lower in the last 2 months of life. Hospitalization contributed 24% to the total expenditure for HHPs and 64% of the total expenditure for NHHPs.

Conclusion: Since the lower cost of care of HPs was due largely to the component of acute hospitalization, particularly in the last 2 months, every effort should be made to expand home-hospice services and reduce hospitalization, especially during the last months of life.
approach, was higher. However, few patients received these services. Every effort should be made to increase the number of patients treated by palliative services at the end of life to improve both the efficiency and the quality of care of these patients.

Abstract number: P164
Abstract type: Poster
Testing for and Treating Venous Thromboembolism: Logistical and Organisational Issues

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Background: Treatment guidelines for venous thromboembolism (VTE) in cancer patients recommend 3-6 months low molecular weight heparin (LMWH). The risk of bleeding in advanced cancer make treatment decisions, which focus on net benefit, complex. We explored factors that influence doctors’ decision-making in this situation. We present the organisational issues that affect these decisions.

Method: Forty-five oncologists, palliative physicians and general practitioners across Yorkshire and South Wales were interviewed about their experiences of managing patients with advanced cancer and VTE, purposively sampled by seniority and specialty. All interviews were recorded and transcribed. Data were analysed using Framework Analysis.

Results: Doctors identified a number of organisational factors that influenced their decisions, especially in those with a short prognosis: the need at times for negotiations with radiology staff and for patients to be re-assessed in A&E; days in hospital awaiting scans; inflexible ambulances; taxing journeys and rurality. However, most were satisfied with diagnostic services apart from out of hours and in some areas innovative services, designed to co-ordinate the process, had been developed to address problems.

Tension existed regarding LMWH prescribing and budgetary responsibility especially if community-prescribed LMWH was restricted. Good inter-sector communication was key to effective LMWH prescribing and fractured care was detrimental. District nurse LMWH administration was seen either as a time-consuming burden or a useful daily visit.

Conclusion: Doctors find management decisions for people with VTE and advanced cancer difficult. Logistics regarding diagnosis (arranging tests, transport, avoidance of days in hospital) and management (prescribing, monitoring, budgetary responsibility, cross-sector working) influence decisions. Smooth access to diagnosis and treatment for people with advanced cancer should be a service priority.

Abstract number: P165
Abstract type: Poster
Cost-effective Enhanced Home-based Palliative Care Service Delivery: Findings from the Niagara West Shared-Care Approach in Ontario (Canada)

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Background: The study described resource utilization and costs of enhanced home-based palliative care delivery under a shared-care approach in a rural area of Ontario (Canada) from the public health care system’s perspective.

Methods: Patient-level data from the Enhanced Palliative Care Team (EPCT), the Community Care Access Center (CCAC) - responsible for service planning and case management - and family physician/Family Health Group as well as emergency room (ER) visits and hospitalizations were combined and analyzed, split by gender and various cancer and non-cancer diagnoses.

Results: Total costs for all patient-related services to the 95 study participants (average age 71 years) over a 15 months period (January 2005 to March 2006) were (2007 Canadian) $1,625,658 - or $17,112 per patient/$118 per patient day. Different resource utilization and cost patterns emerged by gender and disease: Male patients utilized fewer EPCT and CCAC resources than female patients, but had more physician and emergency room visits/hospitalizations. Cancer patients utilized fewer EPCT and CCAC resources than non-cancer patients, but accumulated more physician visits and hospitalizations. Their average costs amounted to $16,034 - or $115 per day in program, compared to $24,571 - or $135 for non-cancer cases.

Conclusion: While higher than expenditures previously reported for a cancer-only population in an urban Ontario setting, the costs were within the parameters of the US Medicare Hospice Benefits, on par with the level-of-care per diem funding assigned to long-term care homes and lower than average alternate level of care and hospital costs charged in the Province of Ontario. Case-mix simulations could assist with future resource and service planning. Funding for the project was provided under the provincial envelope of Health Canada’s Primary Health Care Transition Fund (PHCTF). The analyses were part of a trainee stipend from the CIHR Team in Community Care and Health Human Resources.
Improving Psychological Support by District Nurses in Palliative Home Care: A Pilot Study of a Communication Skills Tool

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Background: District Nurses (DNs) provide support visits over many months to cancer patients before the end of life to assess and monitor them, and provide psychological support. From the literature we know that many cancer patients have unmet psychological needs, and that DNs find psychological support difficult. DNs are reluctant to ask about patients’ emotional concerns as they doubt their ability to deal with them, and are apprehensive about time constraints. SAGE & THYME is an evidence based communication skills tool that addresses concerns about ability and time. It has been piloted in secondary care but has not previously been evaluated in the home care setting.

Aims: To train DNs in SAGE & THYME and pilot its use in palliative home care to reflect on its utility in this setting.

Methods: 30 DNs will receive training in SAGE & THYME. Focus groups will be conducted with three groups of DNs prior to the training to discuss challenges with meeting psychological needs and the potential of SAGE & THYME to improve communication skills, and the same three groups two months after the training to reflect on what they have learned and their use of SAGE & THYME in practice.

Analysis: Transcripts will be fully transcribed and data analysed thematically using NVivo.

Results: Data collection and analysis will be completed by June 2012. We will report findings on DNs’ experiences and challenges of meeting cancer patients’ psychological concerns, and DNs’ reflections on the utility and feasibility of using SAGE & THYME with cancer patients in the home.

Conclusion: SAGE & THYME has the potential to improve the provision of psychological support to cancer patients in the home. This study will provide important understanding of the process of improving communication skills in generalist primary care practitioners. The study also provides essential preparatory work for a future trial to evaluate the effectiveness of SAGE & THYME in improving support for cancer patients by DNs.

Abstract number: P167
Abstract type: Poster

Palliative Care Services in Portugal: What We Need, what We Have and what We Still Need

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Aim: To identify the current palliative care services needs.

Methods:
• We used the data by National Institute of Statistics and by the National Health Department for 2011 (September). We used also, the requirements by the EAPC in your last White Paper and by Gómez-Batiste et al;
• We analyse 18 districts, Azores and Madeira

Results:
• Home Palliative Care Teams: the estimate is 106-158 (mean: 106); we have 10 (in only 6 districts); so we still need 96-148 (mean: 122); 12 districts and the 2 regions don’t have any HPCT
• Hospital Palliative Care Support Team: the estimate is 96; we have 18 (in only 6 districts); so we still need 78; 12 districts and the 2 regions don’t have any HPCST
• Palliative Care Beds, in total: the estimate is 844-1056 (mean: 950); we have 236 (in 13 districts); so we still need 608-820 (mean: 714); 5 districts and the 2 regions don’t have any PCB
• Palliative Care Beds, in acute care settings: the estimate is 253-317 (mean: 285); we have 56 (in only 4 districts); so we still need 197-261 (mean: 229); 14 districts and the 2 regions don’t have any of these beds
• Palliative Care Beds, in non-acute care settings: the estimate is 591-739 (mean: 665); we have 180 (in 12 districts); so we still need 411-559(mean: 485); 6 districts and the 2 regions don’t have any of these beds.

Conclusions: In order to ensure the accessibility to all Portuguese people, we need, as soon as possible, to deliver and to develop palliative care resources as close as possible the patients who need them.

Abstract number: P168
Abstract type: Poster

Basic Quality Indicators for Palliative Care Services in Portugal: 1st Step - A Systematic Review

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Aim: To identify basic quality indicators for palliative care services to submit at the 1st round of Delphi technique with palliative care experts.

Methods:
• We searched studies in computerized bibliographic databases (Medline, PsycINFO and CINAHL) with the follow strategy: (((“Palliative Care” [MESH])
OR “Hospice Care” [MESH] OR “Terminal Care” [MESH: No Exp]) OR “Terminally ill” [MESH] AND (((“Quality Indicators, Health Care” [MESH]) OR “Outcome Assessment (Health Care)” [Mesh:NoExp]) OR “Process Assessment (Health Care)”[Mesh]).

• We use the domains of the National Quality Forum to classify the indicators

Results:

• A total of 673 publications were identified. Based on the title and the abstracts, 87 appeared to fulfill the selection criteria, but after reading the full text, only 26 meet the criteria. One additional publication has been selected by hand search.

• From a total of 363 quality indicators we selected 120 as basic indicators

• These indicators are 23 of structure, 72 of process and 25 of outcomes

• 43 quality indicators belong to the domain “Structure and Process of Care”, 20 to the domain “Physical Aspects of Care”, 14 to the “Psychological and Psychiatric Aspects of Care”, 11 to the “Social Aspects of Care”, 3 to the “Spiritual, Religious and Existential Aspects of Care”, 3 to the “Cultural Aspects of Care”, 15 to the “Care of the Imminently Dying Patient” and 11 to the “Ethical and Legal Aspects of Care”

Conclusions: We found a total of 120 basic quality indicators which must be sent to palliative care experts in order to analyse the adequacy, usefulness and value to use in Portuguese Palliative Care Services.

Abstract number: P169

Abstract type: Poster

How Do our Patients Proceed? Patients' Disease and Care Trajectories after Discharge from Inpatient Palliative Care - A Preliminary Report

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Background: Little is known about the disease trajectories of patients after discharge or transfer from inpatient palliative care to other care settings. This study aims to survey the further care situation and survival of patients. A comparison of patient groups from different care settings is planned to reassess quality of advanced care planning.

Methods: All patients or their legal guardians are asked to voluntarily agree in 4-weekly follow up phone calls to caregivers after discharge from an inpatient PCU in Germany. Inpatient hospices, specialised outpatient palliative care teams and general practitioner are interviewed on the patients’ general condition, symptoms and problems, current medications, integrated health care services, received interventions and hospitalisations. Additionally, survival time and place of death are registered. Follow up is planned for 240 patients.

Preliminary results: From June until September 105 patients were admitted to inpatient palliative care. During this period 40 of these (21 men; 19 women; mean age=66.4, range=26.2 - 91.7 years) were discharged and participated in the study. Patients were discharged to hospices (27.5%), home (55%), nursing homes (10%), rehabilitation or other inpatient medical care units (7.5%).

Only few patients received further chemotherapy (10%), radiation or surgical therapy (each 2.5%), interventions e.g. PCA infusion pump (15%), parenteral nutrition (10%), intravenous medications (10%) and pleura or ascites puncture (5%). Readmissions to hospital or emergency calls occurred in 27.5% of all investigated cases. The mean survival of study participants who died during the follow up time is 18.8 days (range=0 - 66 days; N=27).

Preliminary conclusions: Advance care and end-of-life planning at PCUs can help to avoid aggressive anti neoplasm therapies and burdensome interventions. Further group comparisons between different care settings and diagnoses will be calculated with higher number of study participants.

Abstract number: P170

Abstract type: Poster

Feeding Tube Insertions and Hospital Staffing of the Attending Physician

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Background: Striking variation exists in hospital rates of feeding tube (FT) insertion. We examined whether the specialty of the patient’s attending physician influences this practice.

Methods: Hospitalizations for NH residents with advanced cognitive impairment (defined as Cognitive Performance Score of 4 and higher) with a DRG diagnosis of an infection or dehydration was examined for Medicare Beneficiaries between 2001 and 2007. ICU stays or less than 3 days hospital stay were excluded. The attending physician was categorized: all hospitalists, all general physician non-hospitalists, all subspecialists, and mixture of generalist and subspecialist. In addition, whether or not there was discontinuity between attending physician groups was determined. The association between attending physician group and FT insertion was examined using a hospital fixed-effect multivariate logistic model that adjusted for socio-demographic variables, medical conditions, and orders to withhold life-sustaining treatment.
Results: Over 7 years, 8.4% of 39,675 hospitalizations underwent FT insertion. Hospitalists increased from 21.5% to 52.6% and subspecialist acting as the attending increased 33.3% to 44.8%. Discontinuity of physicians increased from 35.1% to 50.8%. After multivariate adjustment, FT insertion rates did not differ between all hospitalist and all non-hospitalists. However, hospitalizations where a subspecialist acted as the attending physician for all the time or part of time had a higher feeding tube insertion (e.g., 18.3% compared to rate of 2.5% when the physician always a general internist (AOR 7.4 95% CI 5.3-10.2) or when there was discontinuity of the attending physician (AOR 5.4; 95% CI 4.9 -6.1). Conclusions: Among NH residents hospitalized for an infection or dehydration without an ICU stay, feeding tubes insertions are more commonly inserted when hospitals utilizes subspecialist as attending physicians and/or when there is physician discontinuity.

Abstract number: P171
Abstract type: Poster

Patients Experiences with Out-of-Hours Palliative Care: Does Information Transfer from the GP to the Locum Make a Difference?

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Introduction: Out-of-hours service provision in the Netherlands is now delivered by GP co-operatives, as it is in the United Kingdom, Sweden and Denmark. To ensure good quality of care for palliative care patients, continuity of care is essential. Unfamiliarity with the patient and his problems may lead to poor symptom control and inappropriate hospital admissions. In this study we explored whether patients’ experiences were related to the absence or presence of information during out-of-hours care.

Methods: We held structured telephone interviews with palliative patients or their carers after all first out-of-hours contacts with the GP co-operative. A trained research assistant held, after given consent, a telephone interview. We compared cases in which information was transferred from the GP to the co-operative or not.

Results: We held 324 telephone interviews: 37 with the patients themselves, 190 with a family care giver and 97 with a professional care giver. The locum was significantly more often well informed when information was transferred.

When asked if the problem had improved after the action of the locum, 86% said that it did improve. In the group where information was available this percentage was 95%, a significant difference. The locum addressed the reason for encounter also more often in this group, but this result is not significant. No significant difference between the groups was found when asked about the trust in out-of-hours primary care.

Discussion: Palliative patients or their carers find the locum more often well informed when information was transferred to the GP co-operative. They also state more often that there was improvement regarding the problem they called for. It is possible that a locum with information on the patient’s situation is more able to handle a difficult situation. This confirms statements in literature that improved communication between in-hours and the out-of-hours service was crucial in decision making and symptom control.

Abstract number: P172
Abstract type: Poster

Experiences and Needs in Palliative Care - A Qualitative Multiperspective Evaluation Study on Health Care Structures in Lower Austria

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Specialist supportive care is important to provide excellent care for patients with advanced illness and their families over the course of illness. Extensive hospice and palliative care was developed and implemented in addition to usual health care and hospice care in Lower Austria. The aim of this restructing was to provide better qualitative care for patients with advanced illness and their families.

Aims: Aims of this study are to explore retrospectively the provision of health and palliative care during the illness from the perspectives of family caregivers, patient needs and experiences and the professional perspective on the renewal and its realisation.

Methods: Qualitative Research was used to describe the substantial quality of care from four perspectives to explore the experience of patients, familial caregivers, professionals and project management. Qualitative interviews were used to - reconstruct care processes from the perspective of family caregivers (N=21) after the death of their relatives - examine and describe experiences and needs of cancer patients (N=13). Five focus groups were conducted with interdisciplinary clinical and outpatient care hospice and palliative care teams (N=50) to describe their experience with the realisation of the new processes and structures. A focus group (N=6) was carried out to investigate the point of view of the operative project management. To analyse the data content analysis was used.
**Results:** Although the analysing process is still ongoing, first results show important benefits for patients with advanced illness and their family caregivers over the course of illness. Critical incidences are continuity and certainty for patients and families. This requires 24-hour accessibility of the hospice and palliative care teams. The point of transition to palliative health care and access to palliative care teams are often too late, caused by health care system which is mainly focused on curative health care. Founded by NÖGUS.

**Abstract number:** P173  
**Abstract type:** Poster  
**Problems and Training Needs in End of Life Care for People with Intellectual Disabilities**

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**Aims:** In a previous Dutch study it was found that professionals caring for people with intellectual disabilities were experiencing deficits in their knowledge and skills regarding end-of-life care. The aim of this study was to identify changes between 2005 and 2011 in professionals’ views on the state-of-the-art of the end-of-life care for people with intellectual disabilities.

**Methods:** A pre-structured questionnaire was sent to managers of non-medical staff and doctors in organisations for people with an intellectual disability in the Netherlands. The questionnaire was completed by 72 managers (response rate 53%) and 90 doctors (response rate 40%).

**Results:** In 2011 there are more tools available that professionals can use when giving end-of-life care and more volunteers are involved in end-of-life care. The perceived quality of care remains the same, but professionals in 2011 are less satisfied than in 2005 about the involvement of patients in their own care processes. Despite the increase of tools, there are no major shifts in the perceived quality of the care. The main bottlenecks are timely identification and monitoring of pain and other symptoms, too much turbulence in the living environment, insufficient time for the client, and limited opportunities to involve volunteers. The training needs have not much changed either. The greatest need is for training in assessment and management of pain and on how quality of end-of-life care can be assessed. There is also a need for guidelines on dealing with illness and death in different cultures. Finally one would like more tools for assessing symptoms such as anxiety, fatigue, etc. in the final phase.

**Conclusion:** Despite many initiatives to support and improve end-of-life care for people with intellectual disabilities professionals still notice problems and training needs. The results also suggest that professionals are increasingly aware of what is needed for good end-of-life care.

**Abstract number:** P174  
**Abstract type:** Poster  
**Collaboration Challenges in the Transition from Curative to Palliative Care for Patients with Colorectal Cancer**

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**Aim:** To describe patients’ and healthcare professionals’ perceptions of collaboration during the colorectal cancer care trajectory, with an emphasis on the transition from curative to palliative care.

**Study population:** Participants were patients, informal caregivers, health professionals, physicians and managers from primary and secondary/tertiary care (N=43).

**Methods:** Qualitative methods were used, based on Giddens’ theory of structuration (1987). A total of 6 focus groups and 28 individual interviews were conducted. Content analysis was performed.

**Results:** Four different phases were identified in the colorectal cancer care trajectory, each associated with particular challenges related to communication, information exchange and collaboration. Introduced in most Quebec cancer centers, pivot nurses in oncology (PNOs) are perceived as key actors to improve continuity of care. However, some deficiencies related to resources, structure and organization of care still remain. In particular, the transition between curative and palliative care seems vaguely defined and, consequently, rarely discussed openly with patients. Referrals to palliative care consultants are made late in the process of care. At the advanced/end of life phase, the responsibility of care is transferred from hospital-based secondary/tertiary care to community-based primary care. Information exchange is often incomplete and/or delayed. Referrals to homecare services are also made quite late, which may result in fragmented care, frustration from health professionals and dissatisfaction of patients and their family caregivers.

**Conclusion:** To improve continuity of care, there is a need to implement some organizational strategies, in addition to PNOs, like the development of communication tools and mechanisms to increase information exchange particularly between primary and secondary/tertiary care.

*Study funded by the Quebec Ministry of Health and Social Services, in Quebec City*
Aims of Case Management in Palliative Care in the Netherlands. Results from an Expert Panel Study

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Introduction: Case management is a heterogeneous concept of care, in which an individual or small team is responsible for navigating the patient through a complex process while meeting the patient’s needs. This study examines the aims of case management for patients living at home in palliative care in The Netherlands.

Design and method: The concept of case management was explored by consultation of an expert panel. A modified version of the RAND®/UCLA appropriateness method was used. In three rounds the expert panel composed and rated a list of aims and characteristics important for case management in palliative care. A total of 76 health care professionals, researchers and policy makers were invited to join the expert panel, of which 61% participated in at least one round.

Analysis: Agreement was reached when the experts agreed with the aim and with each other (this was calculated following the procedure described by RAND corporation).

Results: Nine out of ten aims of case management were met with agreement. These nine aims are: care is aimed at quality of life and death; care starts when needed and lasts until the patient is deceased and their significant others have received bereavement support; care is tailored to the individual needs and wishes of the patient and their significant others; content, duration and frequency of contacts are adjusted according to the needs of the patient and significant others; the relationship with the patient and significant others is personal; care is comprehensive; there is ongoing sufficient and clear communication between all involved in care with and for the patient; care is accessible; case management is part of primary care.

Conclusion: The aims of case management are in accordance with the general principles of palliative care and reflect the patient advocacy model of case management. The aims also underline the importance of the seven dimensions of continuity of complex care formulated by Bachrach.

Number and Characteristics of Case Management in Palliative Care in the Netherlands. Results from a Nationwide Survey

van der Plas A.G.M.1,2, Deliens L.1,2,3, van de Watering M.1,2,4, Jansen W.J.1,2,6, Vissers K.7, Onwuteaka-Philipsen B.1,2

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Aims: Case management is a heterogeneous concept of care, in which an individual or small team is responsible for navigating the patient through a complex process while meeting the patient’s needs. This study investigates the number and characteristics of initiatives for case management in palliative care in The Netherlands.

Design and method: Data were gathered in 2010 through a written questionnaire and an additional interview by phone. All 50 palliative care networks coordinators were contacted and asked whether they knew about case management initiatives. If so, the coordinator provided contact information of the person directly involved in this initiative. Through snowballing additional possible initiatives were identified. We conducted 33 interviews and received 30 questionnaires.

Analysis: Descriptive statistics were calculated for all characteristics.

Results: We identified 20 initiatives for case management in The Netherlands. Main ingredients of care are advocacy, identification of needs and preferences of patients and significant others, offering information and support, and organising care. Hands-on care is delivered by a minority of case management initiatives. Care is offered complementary to other care, not as a substitution. Most case managers work in a team of case managers (not in a multidisciplinary team) and offer other services besides case
management. Variation in type of organisation delivering case management (eg hospice or home care organisation) and target group for case management is high.

**Conclusion:** Within 20 identified initiatives content of care shows little variability, most variation in case management can be seen in the way care is structured. Research into effects of implementation on collaboration with family physicians and district nurses and how care is perceived by patients and those close to them, may help health care planners to make informed decisions on the best way to deliver case management.

Abstract number: P177
Abstract type: Poster

**Use of a Tertiary Referral Radiotherapy Centre Day Ward**

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**Background:** St. Luke’s Hospital, Dublin is a tertiary referral radiotherapy centre with a varied patient cohort. With the implementation of the National Cancer Control Programme, there is significant change underway in how and where patients receive treatment. In order to assess the effect of this change on our palliative patient population, we undertook a review of the use of the oncology day ward facility in our hospital.

**Aims:** To identify the reasons for attendance of patients to an oncology day ward in a tertiary referral radiotherapy centre.

**Methods:** We identified all patients who attended the day ward over a one month period (June 2011) from the day ward admission record. We reviewed the medical notes of each attendee. Characteristics including primary diagnosis, chemotherapy, radiotherapy, aim of treatment and reason for attendance were collected.

**Results:** 188 patients attended the day ward during June 2011. When multiple attendances were factored in, there were 299 attendances in total. 33.4% (100) of these attendances were for chemotherapy administration, of which 21 were for patients being treated with palliative intent. Overall, 86 patients (119 attendances) were being treated with a non curative intent. Reasons for attendance other than chemotherapy included cannulation, bisphosphonate infusion, intravenous fluid administration, medical review, procedures (including nerve block, colonoscopy, biopsy and peripherally inserted central catheter (PICC) facilitation) and blood transfusion. A number of patients attended for more than one reason.

**Conclusion:** Although chemotherapy administration is the primary reason for attendance to a tertiary centre day ward, our patients attended for multiple other reasons. The care needs of the population of patients on ongoing active treatment with chemotherapy or radiotherapy but with palliative needs must be considered in the transformation of services.

Abstract number: P178
Abstract type: Poster

**A Conceptual Framework for Integrated Palliative Care Interventions: Understanding when Pathways Work, Don’t Work and why**

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**Background:** Multiple professionals deliver palliative care and a range of tools exist to promote integration across service boundaries. Integrated care describes a variety of complex interventions which address diverse objectives. We wanted to establish the conceptual framework underpinning such interventions in order to optimise their use within palliative care.

**Methods:** We developed an analytical framework following realist review principles. Studies of relevant integrated care interventions were classified, in respect of key differentiating characteristics, as chain, hub or network models. We mapped the features of situations in which they were successful and identified the active components or mechanisms that effected change.

**Results:** Terms such as care pathway and programme were unhelpful as they applied to heterogeneous groups of interventions which combined different components not always suited to the context in which they were applied. Chain interventions were effective in acute or elective care, with unambiguous entry points for clearly defined patients groups and outcomes, with high stakeholder consensus, following predictable timelines. Hub and network models were more effective for chronic patient centred care following unpredictable time courses, when entry points and patient groups were less clearly defined, and when outcomes and interventions required negotiation. Applying this framework to palliative care interventions (e.g. Liverpool Care Pathway) revealed which model might be effective depending on the ‘problem’ of integration addressed.

**Conclusions:** Palliative care contexts resemble situations in which hub and network models are more likely to achieve intended outcomes. Existing integrated care interventions in palliative care are often amalgams of all three models which may explain their shortcomings and inconsistent uptake in practice. Our findings can be used to develop integrated palliative care interventions and modify existing tools.
**Abstract number:** P179  
**Abstract type:** Poster  
**Structure of Palliative Care Hospital and Home Support Teams in Austria 2010**  
**Pelttari L., Pissarek A.H., Zottele P., Baumgartner J.**  
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**Research aims:** The concept of graded Hospice and Palliative Care services in Austria comprises Palliative Care Hospital Support Teams (PCHospT) and Palliative Care Home Support Teams (PCHomeT). A work group of the Austrian ministry of health defined the need for full supply. The study describes the degree of realisation of these services, differences in organisational structures of existing PCHospT and PCHomeT in Austria in 2010 and shows ways to improve future developments.

**Study design and methods:** A questionnaire was sent to all PCHospT and PCHomeT to collect the necessary data.

**Results:** PCHospT in Austria are realised to a degree of 28%, PCHomeT to a degree of 58% taking in account the number of full time equivalents (FTE).

In 2010 35 PCHospT worked in Austria. 15 of them were stand-alone PCHospT’s, 16 worked as a combined PCHospT/PCHomeT and 4 were linked to a palliative care unit. 5 PCHospT supported two hospitals, 2 of them three hospitals and the majority supported only one hospital. Most of the teams work in hospitals with 100-500 beds, one has 50 and 4 over 1000 beds. PCHospT cared for 8110 patients, 86% were oncological patients; the majority of the patients went home. 202 persons (83.5 FTE) worked as PCHospT members.

PCHomeT: In 2010 36 PCHomeT worked in Austria. They cared for 7757 patients, 81% of them were oncological patients. The majority of the patients died. 362 persons (156.3 FTE) worked as PCHomeT members. In some cases team members (physicians, social workers) work on the basis of a service contract and are not included in this statistics.

**Conclusions:** Financial considerations favour the combined version of PCHospT/PCHomeT and are behind a PCHospT’s responsibility for more than one hospital. Challenges are smaller hospitals in remote areas. When assessing the degree of realization of PCHomeT one has to combine the number of teams, the FTE and the regional setting (mountain valleys create different accessibility conditions compared to big cities).

**Introduction:** While international research on palliative care has begun to develop over the past decades, it has not kept pace with the growing demand for high quality care. To meet the societal challenges accompanying the dramatic increase of patients facing the need for good palliative care in the forthcoming decades, there is an urgent need for enhanced collaborative research training in palliative care. This generation of researchers and the next is to be provided with the best possible skills to improve evidence based palliative care and influence palliative care policies at national and international level.

EUROIMPACT aims to develop a multi-disciplinary, multi-professional and intersectorial educational and research training framework in Europe aimed at monitoring and improving the quality of palliative care in Europe.

**Methods:** EUROIMPACT is a Marie Curie Initial Training Network funded under Framework Programme 7 of the European Commission. With 11 partners from universities, socio-economic and private partners and several European umbrella organisations all at the forefront of palliative research and representing a wide spectrum of disciplines and professions.

**Discussion:** EUROIMPACT is currently training 12 junior and 4 experienced researchers from a wide range of EU countries. On-the-job training will be supplemented with structured courses concerning palliative care research and network-wide trainings on multidisciplinarity, ethics, cross-national research and societal dissemination. EUROIMPACT will bridge the gap between research institutes, multiple disciplines and different sectors and enhance cross-fertilization of research activities leading to a reduction of fragmentation on a topic of great EU relevance. As a result, EUROIMPACT will build the basis for the further development of an EU platform for palliative care PhD research training and increase the international mobility of palliative care researchers across Europe.

**EUROIMPACT: An International PhD Training Programme in Palliative Care Research**

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Abstract number: P181
Abstract type: Poster

Comprehensive Cancer Care & Early Integration of Palliative Care: International Recommendations and Local Experience

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Introduction: The integration of palliative care (PC) early in the disease trajectory of life-limiting cancer is explicitly recommended by the WHO, ASCO and EAPC. Here, the findings of an evaluation of early PC integration into cancer care at a major comprehensive cancer center are presented along with the guidelines (standard operating procedures; SOPs) that were subsequently developed to improve early integration and cooperation of oncology and PC.

Methods: The WHO recommendation to integrate PC early in the trajectory of the disease was accepted in our Center. After two years, a retrospective systematic chart analysis was performed in order to assess how early PC was integrated into cancer care in clinical reality. Subsequently, interdisciplinary oncology project groups developed concise recommendations (SOPs) for standardizing the oncology-PC-cooperation and early integration.

Results: Of the 862 patients receiving PC support, most were already in a reduced physical state (ECOG 3 & 4: 40%) and experiencing burdening symptoms (e.g. dyspnoea 27%). As a result SOPs that were developed and approved by the interdisciplinary working groups now provide (for meanwhile 21 hematonoologic diseases)

(i) disease specific time points for PC integration,
(ii) a clear cut terminology to distinguish PC for example from “best supportive care”,
(iii) prerequisites (e.g., infrastructure, competence, attitude) and
(iv) specification of PC assignments to avoid misunderstandings and conflicts.

Conclusion: Major international institutions state that caring for patients with life-limiting cancer poses a major challenge to the personal and institutional requirements. Interdisciplinary care as the cooperation of oncology and PC has been identified to provide enormous potential to overcome these challenges. With the provision of these SOPs (Gaertner J et al Supp Care Cancer 2011) the authors hope to facilitate the implementation of close PC / oncology cooperation at other centers.

Abstract number: P182
Abstract type: Poster

Developing Research in Independent Hospices: How You Can Make it Happen

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Aim: This workshop aims to share our experience of developing a cross-organisational commitment to supporting research for patients and families within independent hospices. For practitioners working in Specialist Palliative Care it is critical that organisations work together to overcome the barriers of indemnity, lack of resources and organisational difference, to achieve compliance with research governance and policies.

Methods: Faced with the logistical challenges of conducting research in the independent sector, policy and procedures were developed and agreed using lessons learnt from the acute sector. This provided a robust governance framework to facilitate practitioners to engage in research activity within our seven hospices, through extensive collaborative working.

The workshop will launch our tool kit aimed at facilitating hospices who are passionate about improving the quality of palliative care for patients and want to contribute to building an evidence base. The tool kit will share our research governance framework: collaborative working between independent hospices, a local acute hospital research management team and pharmacy, legal services, insurance brokers and human resources. Systems were established to ensure timely approval of projects to protect patients and minimise organisational risks to allow engagement in ‘home grown’ and industry-funded studies.

Results: Since 2008 our group of hospices has approved 7 studies and 1 of the hospices has been involved in a Medicines Health Regulatory Authority inspection.

Conclusions: We wish to share our experiences and share learning with others so that research in independent hospices can become the norm. We need an evidence base to help us support patients with specialist palliative care needs and it is vital that research with these patients is conducted.

Abstract number: P183
Abstract type: Poster

Policy and Human Experience in Rural Complex Chronic Illness
The human and societal burdens associated with chronic illness are pronounced in Appalachia where rates of co-morbidity, disability, and premature death are among the highest in the nation. Little is known about the need for or the feasibility of integrated palliative care in rural areas. This paper reports first year findings from an ethnographic study investigating the intersection of rural culture, policy and human experience in rural complex chronic illness.

Criterion-based sampling was employed to select 33 participants with complex chronic heart and lung conditions from home-health and hospice settings. In-depth, semi-structured interviews with participants, their caregivers, and health professionals were recorded and transcribed verbatim. Data were organized by respondent group using Atlas.TI for data management. The domains of palliative care and the concept of transition were used as a start list for semantic content analysis.

Navigating care structures, processes, and transitions were universally exasperating, albeit from different perspectives. Finances, personal preferences, transportation, and program eligibility were common barriers to care. Rugged individualism, realism, self-reliance, and importance of kin and place served as both barriers and facilitators to optimal care. Emergent themes included fear of progressive dependency, preferences for non-medical self-management tools, and struggle to balance needs of self and kin.

Significant disparities in rural complex chronic illness outcomes exist that are often policy-induced and culturally mediated. Formal care structures and processes are poorly articulated with patient and caregiver needs and preferences. These and other barriers to optimal care are complicated by geography, lack of transportation, strained health infrastructures and poor communication between lay and professional caregivers.

Abstract number: P184
Abstract type: Poster

**Palliative Care for People Living with HIV/AIDS in Uganda: Staff and Stakeholders’ Perspective**

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**Background:** The immense needs for palliative care because of HIV/AIDS epidemics mean that palliative care needs to be provided to all who need it at generalist and specialists levels (Harding & Higginson, 2004). However, despite the government’s endorsement of palliative care activities through its policies, there are still perceived barriers and challenges related to its implementation which are yet to be explored.

**Methods:** As part of a larger study, using a qualitative approach, 10 palliative care staff members recruited at Hospice Africa Uganda participated in individual interviews and one focus group to explore the challenges they faced in delivering services to patients. By the use of interviews with 7 key stakeholders, the broader context of palliative care policy development and opinions about key priorities for the future were explored.

**Findings:** Palliative care staff indicated two categories which broadly covered the challenges of palliative care delivery to PLWA in Uganda: service-linked and provider-linked challenges. Palliative care staff and key stakeholders identified strategies to respond to palliative care needs for PLWA across four dimensions:

- a) partnerships or networking together with stakeholders;
- b) improving palliative care education;
- c) raising awareness of palliative care among communities and health care workers;
- d) advocacy and policies which support and strengthen initiation and expansion of palliative care services to PLWA, including the availability of morphine.

**Conclusion:** Both palliative care staff and key informants’ perspectives highlight successes, barriers and important lessons for palliative care service delivery in Uganda. These lessons have several implications across the dimensions of practice, education, policy and research. The study indicates the need to translate government policies on palliative care into action.

Abstract number: P185
Abstract type: Poster

**Legal and Policy Barriers to Opioid Availability in 12 European Countries: Results from a WHO Self-assessment Checklist for National Situation Analysis**

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Aims: A sound analysis of legal and policy barriers to opioid availability is a prerequisite for improving access to opioids on a national level. The WHO Guidelines “Ensuring balance in national policies on controlled substances” include a country assessment checklist for analysing potential barriers to opioid availability. Within the ATOME project it was aimed at having country teams from the 12 target countries complete the checklist as a basis for their national action plans on improving access to opioids.

Methods: The teams were invited to complete the checklist and thereby explore to what extent the WHO Guidelines are met in their country. Each item of the checklist can be answered with yes/no/unknown, to be specified with explanations and a note as to whether action is required for that specific topic.

Results: To date, checklists from 8 countries are available for analysis. The results show that practical barriers do not always coincide with the formal/legal positive provisions for access to opioids. For example, 1 country stated that despite having a provision in their law that controlled medicines are absolutely necessary for medical and pharmaceutical care, health care professionals could not be free from fear of investigation, prosecution or disproportionate punishment when prescribing or administering opioids. Likewise, 2 countries reported an absence of training courses on rational use of controlled medicines for physicians, pharmacists and nurses whilst having a government policy that urges medical, pharmaceutical and nursing schools to provide education on this issue.

Conclusion: The results confirm findings from previous research that there may be discrepancies between the legal provisions regarding rational use of opioids and the actual barriers in medical practice. The findings highlight the need for a combined approach on the levels of legislation, policy, health care and education for an effective improvement of access to opioids for medical use.

Abstract number: P186
Abstract type: Poster

Pilot Study on Cancer Treatment Accessibility in Cameroon

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Aims: Characteristics of under development especially poverty has greatly handicapped the Millennium Development Goals (MDG) that targeted the neonatal, infant and child mortality. There are still very serious problems of accessing drugs for chronic illnesses like cancer especially in children. Opioids, chemotherapeutic agents, diagnostic and treatment /care centres are still very rare in Cameroon. Cameroon lies on West Africa, described on the MDG goal as the region with the worst world children and infant mortality rate, yet like any other African country, the global recession has hit another hard blow even to the governments.

Methods: Understanding the the hurdles in cancer care in Cameroon through health units visits, survey questionnaires and national population statistics analysis.

Results: Up to about 65% of Cameroonian live in poverty and are deprived of health amenities providing care to chronic diseases like cancer, HIV/AIDS. Palliative care is also lacking greatly and no modern approach to cancer care is available; such as with multidisciplinary approach in many modern institutions. There is neither any national cancer nor palliative care society(www.indexmundi.com/cameron/population). 48% of 18 million (Cameroon population) live below the poverty line of one US dollar per day of which 52.1 percent are in rural areas.

Conclusion: Most hospitals’ services here are unaffordable and unaccessible to the population especially the rural masses and sometimes characterized by bribery and corruption. Modern institutions of care are few but located in the capital cities: very expensive with few professionals. Affording opioids or chemotherapeutic agents is not really within the reach of a large ratio of Cameroonians though scarce, consequently obliging the masses to stick to traditional practices and care which are dangerous. This portrays the great challenges, the tasks awaiting professionals and the great need for partnership, funding and research.

Abstract number: P187
Abstract type: Poster

Evaluating the First Year of a National Service providing Medicines Information for Palliative Care

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Aims: To examine the work of a new national medicines information (MI) service which responds to enquiries (enqs) about medicines in palliative care (PC) and to gain
an insight into the information needs of health professionals using the service. The service is provided by pharmacists at a specialist centre for PC in Ireland.

**Methods:** Information was extracted from the database of enquiry responses. Enqs were categorized according to the symptom they related to and according to type of information requested. Time spent on responding to information requests was evaluated.

**Results:** Total number of enqs received since national launch of the service was 292. At least 59% were from practitioners working in specialist PC. 17% of enqs were from practitioners in primary care. Doctors submitted 39% of enqs, while 33% and 28% of enqs were received from nurses and pharmacists respectively. 45% of enqs related to medicines for pain alone or to medicines for pain and other symptoms. Drug administration and dosage formed the largest category of enquiry. Information on equianalgesic doses of opioids was sought in 10.3% of enqs, while 9.9% related to compatibility of injectable medicines. Ranked in accordance with UKMi guidelines, 88% of enqs were complex (level 2 or 3), defined as requiring review of multiple sources and often requiring professional judgement. Proactive activities included development of patient information leaflets and PC guidelines. Average time spent on responding to an enquiry was 3.75 hours and total time spent over one year was 1,095 hours.

**Conclusion:** Data from the service demonstrates demand among health professionals in Ireland for a medicines information service for PC. When compared with medicines for other symptoms, demand for information on medicines for pain predominated. The complexity and time-intensive nature of enqs may be related to high numbers of enqs about unlicensed use of medicines, of which further review is proposed.

**Abstract number:** P188

**Abstract type:** Poster

**End of Life Decisions and Advance Directives (AD) in Switzerland: A Prospective Study to Better Understand the Role that Patients and their Informal Caregiver (IC) Wish to Play**

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**Introduction and objectives:** There is a growing emphasis on patient’s rights to make decisions about treatment options. However, despite a widespread legislative and professional endorsement of AD, few patients have completed their AD should they become incompetent. In addition, the role of IC in decision making is changing, but little is known on this topic in Switzerland (country with four different cultures and background).

Aims of this study are to better understand which patient’s features impact on their decision to complete AD or not in different parts of Switzerland, to better understand the degree of authority patients expect from their IC and from the health professionals.

**Method:** Prospective study conducted in 4 palliative care units. 150 patients will be included (advanced oncological disease, fluent in French and MMSE ≥20). They will receive information about AD and designate an IC. Demographic data, symptom burden (ESAS, HADS), spiritual well-being (FACTsp) will be assessed. A structured questionnaire will be completed by patient and designated IC.

Preliminary results of 81 included patients (34M-47W, mean age 71±11): 19 patients have completed their AD. Completion of AD was associated with lower anxiety and symptom burden (P<0.05), but not with demographic data and FACTsp score. Results of the questionnaire demonstrated that 57 (71%) patients were satisfied about the medical informations they received, 30 (38%) were not willing to about the future, 34 (42%) wanted a shared decision-making with their physician. Should they become unable to communicate, 50 (63%) expected their surrogate to transmit their own wishes, but only 24 (30%) had spoken recently with them about it.

**Conclusions:** These preliminary results illustrate the paradox of patients who wish to be active in decision making, but only seldom transmit their wishes to IC or complete a written document. Much anticipation work is still needed with patients and their IC.

**Abstract number:** P189

**Abstract type:** Poster

**Does Talking about Spiritual Issues Distress Research Participants?**

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**Background:** The EORTC Quality of Life Group is developing a measure of spiritual wellbeing (SWB) for palliative care patients with cancer. Spiritual care is often understood as accompanying someone as they seek to find meaning in what is happening to them. However, at times health care professionals are reluctant to initiate discussions of spiritual concerns with patients, in some cases due to concern that doing so may cause patients distress. For similar reasons, some ethics committees are hesitant to grant ethical approval for studies which investigate such
sensitive areas. This paper considers findings from pilot-testing the EORTC SWB measure in the UK, and what these suggest for the issue of distress.

**Method:** 3 phases of developing the measure have been completed. Phase I identified relevant issues. Phase II operationalised issues into items. Phase III pilot-tested the items. In the UK, Phase III debriefing interviews with patients were tape-recorded, transcribed, and qualitatively analysed.

**Results:** Several UK respondents showed signs of distress while taking part in the pilot-testing interviews, and some became tearful. All who did so were asked if they wished to cease participating. However, all said that they wished to continue, and all expressed gratitude at the end of the interviews. One said: “Being referred here [the hospice] is the best thing that’s ever happened to me; the socialising and the support. Thank you for listening to me,” and another said simply: “Thank you.”

**Conclusion:** Data from UK pilot-testing of the EORTC SWB measure suggest that research participants may experience discussing spiritual issues as supportive rather than of itself distressing. It seems likely that people facing the ends of their lives are already distressed, and discussion of these matters, rather than causing distress, instead enables participants to express, and thereby perhaps in some way address, the distress they are already feeling.

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**Abstract type:** Poster

**Raising Awareness of Research in Palliative Care to Clinical Teams - The Roadshow**

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**Aim:** To ensure specialist palliative care clinical teams across Wales are aware of research development and research recruitment opportunities and thus maximise access to palliative care research for all patients in Wales.

**Method:** A series of roadshows with multidisciplinary palliative care teams took place at locations selected by the local clinical lead, at lunchtimes, and lasted 1-2 hours. The panel of speakers took the audience through a research project from idea to completion, using a real life example, highlighting the support available at each stage. The presentation was supported by leaflets with details of the primary contact for further information.

**Results:** Feedback was overwhelmingly positive, the majority of attendees had little or no prior research experience. Their comments reflected that this was not through lack of interest, more due to a lack of awareness of research development, or an impression that the process was overly complex and time consuming. The fact that a research support system is now in place was very well received. Meeting the roadshow team and being introduced to their local research network managers was also very helpful. A palliative care database has been established to keep the community up to date with research opportunities and identify clinical champions. Several clinicians have since contacted the group with their research ideas and proposals have been developed to increase research nurse capacity and address research governance issues on a Wales-wide basis.

**Conclusion:** The roadshow initiative represents a unique approach in the UK to raising research awareness amongst clinical palliative care teams. It has introduced multidisciplinary clinicians to local research teams who can provide advice and support. The roadshows have been the first step in developing good communication links, establishing a database of clinical champions and facilitating a coordinated approach to research governance and patient access across Wales.

**Abstract number:** P190

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**Palliative Care in the Acute Hospital Setting: A Qualitative Interview Study**

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**Aims:** The aim of this qualitative study was to explore the perspectives of patients, identified as having palliative care needs, on the care they had recently received while in hospital. Researchers wanted to find out whether any transition from active to palliative care had been discussed or initiated with the patients; the views of the patients on this discussion (or lack of); and the ways in which the patients themselves interpreted their needs, palliative or otherwise.

**Methods:** Sixteen patients with palliative care needs (identified using the Gold Standards Framework) participated in semi-structured interviews post-discharge to explore their views and experiences of a recent hospital admission. Patients were identified during a survey of palliative care need at two UK acute hospitals. Data were analysed using the principles of thematic analysis.

**Results:** Findings indicated that most hospital admissions were emergency/crisis led, and a palliative approach to care was rarely evident. Patients reported particular issues relating to
(1) continuity of care, both within the hospital setting and after discharge;
(2) communication between care providers in secondary care, and communication with the patient;
(3) communication between primary and secondary care.

**Conclusion:** The palliative care needs of patients within the acute hospital setting may not be identified or adequately addressed. Improved communication and continuity of care are necessary to ensure that patients’ palliative care needs are met. There may also be scope to benefit some patients by adopting a more open approach to the awareness of dying. The study also highlights a need to further define and expand the role of generalist palliative care providers in acute hospitals.

**Abstract number:** P192
**Abstract type:** Poster

**Death Declaration in the General Pediatric Setting in an Urban Hospital in Mumbai - The Residents’ Perspectives**

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**Aim:** The study aimed to obtain in-depth understanding of the residents’ perspectives about breaking news of the actual or impending death of the paediatric patient to the family, in a teaching Hospital in Mumbai, India.

**Methodology:** This was a qualitative study based on the grounded theory paradigm. Seven residents were interviewed. The interviews were transcribed verbatim and personal narratives constructed. Data collection and interpretation occurred simultaneously and guided further theoretical sampling. Major categories and their subcategories were identified by coding procedures. Emerging categories and subcategories were interconnected using selective coding.

**Results:** The categories were- Practice, Attitudes, Relationship with the Patient and Interactions with the Family. Preparing family members, effective use of language, gaining the family’s trust facilitated breaking bad news. Anticipated aggressive or highly emotional responses of families were perceived as a barrier. Residents valued role models and experiential learning more than formal training for learning communication skills. Previous interactions with patients affected the emotional responses of the residents to the patient’s death. Residents’ personal experiences of loss or parenthood affected the way they broke bad news to families. Residents acknowledged lack of support for bereaved families but considered their own role to be restricted to physical care.

**Conclusion:** The study helped to identify multiple factors that influence the way residents break news of a paediatric patient’s death to the family. The findings of this study can form the basis of further research and may be used to develop recommendations for improving communication between resident paediatricians and families of critically ill children.

**Abstract number:** P193
**Abstract type:** Poster

**Palliative Care Information Needs in Central and Eastern Europe and the Commonwealth of Independent States**

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**Aims:** Access to published information including medical journals and educational opportunities is regarded as essential for health care professionals providing palliative care (pc). In many countries, access is difficult due to financial problems and language barriers. To ensure equal access to pc information across Europe, the European Association for Palliative Care undertook a survey on pc information needs in 28 countries in Central/Eastern Europe (CEE) and the Commonwealth of Independent States (CIS).

**Methods:** A questionnaire was developed in English and translated into 15 different languages. The survey was available both online and as a hard copy version. It was distributed via the national hospice and pc associations.

**Results:** To date, 91 health care professionals from 12 countries completed the questionnaire. The majority were physicians (36%), nurses (27%) and psychosocial staff (20%). Most of the predefined types of information (clinical issues, specific care populations, psychosocial issues, education, policy & legislation) were rated as relevant by the respondents with 4 topics standing out: legislation/official papers (69%); education courses in pc (68%); fundraising for projects/organisations (63%); and patients with specific diseases (60%). At the same time respondents found information on these topics most difficult to access. The development of a good website (80%), an electronic newsletter (73%), and regular meetings or conferences (68%) were seen as the most important options to keep oneself updated about pc - preferably in the respondents’ own language.

**Conclusion:** The findings suggest that information helping to strengthen the strategic, financial, and professional
power of pc in their country has the highest relevance for health care professionals in CEE and the CIS. The results will support a targeted planning of information provision, educational opportunities and dissemination strategies to promote further pc development in these countries.

**Abstract number:** P194  
**Abstract type:** Poster  
**Communicating with Patients about their Feelings and Preferences for the Future in Palliative Care: A Systematic Review of Evidence from Social Science and Linguistics**  
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Communicating with patients about their feelings and preferences for the future in the context of uncertainty is a challenging element of palliative care. Useful evidence about how to do so exists, but most is embedded in social scientific rather than clinical research.  
**Aims:** To collate evidence about communication practices from social scientific research involving study of tape recorded conversations with patients. To use the evidence to inform policy, practice and training to aid clinicians responsible for talking with patients about their future options, including advance care planning.  
**Methods:** This innovative systematic review spanned social science, clinical and linguistics research. Using explicit inclusion and exclusion criteria, we searched electronic databases and specialist sources. We used review and synthesis techniques appropriate for social-science research.  
**Results:** 2,026 publications were initially identified. Of the 21 meeting the inclusion criteria, 9 were social science, 5 clinical and 7 linguistics publications. Strong evidence (10/21) indicates hypothetical questions are effective in encouraging people to address feelings and plans for uncertain and difficult futures. Moderate evidence (5/21) indicates that another way to create such opportunities entails using cautious, euphemistic language; and that doing so provides distinctive opportunities for people to deflect or avoid the topic. Moderate evidence (3/21) indicates that people often steer such conversations towards more optimistic statements, which tends to stop further talk about difficult events.  
**Conclusions:** Social-science, linguistic and clinical evidence is available to inform this skilled, complex, often problematic element of care. There are different ways to provide opportunities to discuss feelings and plans in relation to end of life. Different ways have different results: better understandings of these will facilitate evidence-based communication.

**Abstract number:** P195  
**Abstract type:** Poster  
**Determinants of Prognosis Disclosure for Non-hospice Terminally Ill Cancer Patients in Taiwan**  
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**Background:** Adequate knowledge of the prognosis is a prerequisite for planning appropriate treatments to support one’s own values and limit the use of “futile” interventions to prolong unnecessary suffering, thus improves quality of life (QOL) at end of life (EOL). However, a “family-consent for disclosure” approach is commonly practiced based on the assertions of filial piety and the relative power of family in Taiwan despite there is evidence that Taiwanese cancer patients’ information needs for prognosis are substantial. The purpose of this study was to investigate determinants of prognosis disclosure for terminally ill cancer patients in Taiwan.  
**Methods:** A convenience sample of 2,173 terminally ill cancer patients not under hospice care from 24 hospitals throughout Taiwan were one-time surveyed. Determinants of prognosis disclosure were identified by multivariate logistic regression analysis using the generalized estimating equation method to account for correlation in the error term due to clustering of individuals in the same hospital.  
**Results:** Only 35.07% of the patients indicated that they had been informed of their prognosis by their physicians. The likelihood of being informed of prognosis was higher for terminally ill cancer patients who were:  
(1) younger than 75 years old,  
(2) married, and  
(3) with an educational level ≥ junior high school, other chronic diseases, and a higher level of QOL.  
However, prognostic information was significantly less likely to be disclosed to newly diagnosed (1-2 months) patients than those who had survived over two years.  
**Conclusion:** Health care professionals shall honor the information preference for those who wish to know about their prognosis, especially for those cancer patients who are at risk of not being informed as identified in this study. Equipped with and empowered by adequate information, terminally ill cancer patients may have better opportunities to make EOL care decisions that are in accord with their own wishes.
Cultural Differences in the Causal Attributions of Multiple Sclerosis among Black Caribbean and white British People with MS

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Background: In the UK prevalence of multiple sclerosis (MS) is thought to be increasing among black and minority ethnic (BME) groups. There is growing evidence that perceptions of illness causation influence adjustment and attitudes to service use. No research has examined how BME groups understand their MS.

Aim: To explore illness beliefs among black Caribbean (BC) and white British (WB) people severely affected by MS, and understand how these may be culturally patterned.

Method: Semi-structured qualitative interviews were conducted among BC and WB people with MS (PwMS). Data were analysed using the framework approach.

Results: 15 BC and 15 WB PwMS with an EDSS of ≥6.0 (severe disease) were interviewed (mean ages of 46.6 and 56.9 yrs respectively). Causal attributions were complex, with most PwMS reporting multiple explanations to account for their MS. PwMS from both ethnic groups provided ‘logical and scientific’ accounts; these included genetic/viral influences, stress, the environment, and lifestyle factors. Familial history of MS was specific to WB PwMS, while some BC PwMS referred to bodily insults, for example injuries. Traditional ‘supernatural’ attributions departed biomedical perspectives and included religious challenges or tests from God. Although these views were cited more frequently by BC than WB PwMS, the notion of punishment was not always fully endorsed by them. While ‘fate/destiny’ accounted for another lay attribution specific to BC PwMS, where MS was believed to have been written into their life plan, PwMS from both groups also specifically to BC PwMS, where MS was believed to have been written into their life plan, PwMS from both groups also acknowledged the possibility of bad luck or randomness specific to BC PwMS, where MS was believed to have been written into their life plan, PwMS from both groups also acknowledged the possibility of bad luck or randomness

Conclusion: We identify important cultural differences of MS causation. ‘Impeccable assessment’, central to the principle of specialist palliative care and neurology, must incorporate cultural relativism that identifies and values social difference. This should enhance concordance with treatment and care as disease progresses. Funded by MS Society, UK.

The Burdens of Hope

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Background: Although patient studies usually approach hope because of its helpful effects, almost no attention has been paid to the burdens of hope. If these burdens were better identified and described, professionals could be supported in their communication and develop strategies to relieve these burdens.

Aim: To explore the burdens of hope among palliative care patients.

Method: Prospective interview study. We used theoretical sampling, seeking for variation in age, sex, disease and housing and stopped our inclusion after we had reached saturation. The semi-structured interviews were transcribed. Using a hermeneutic phenomenological approach, we thematically analyzed the data and then focused on the role of hope. Two researchers independent from us and each other, coded some interviews and we then discussed our analyses until we reached consensus.

Results: 11 incurable cancer patients, 8 severe COPD patients and 4 severe heart failure patients (N=23) were included (12 men, 11 women). Mean age: 66 yrs (37-91 yrs). Interviews lasted between roughly 10-90 minutes. In the first place, patients felt a pressure to hope and to fight on because they felt responsible not to leave their family members behind. Second, they hoped and fought to stay alive, but simultaneously hoped to surrender to death and dying, which led to internal tensions. A third burden related to hope concerned the physical discomfort patients experienced because they hoped to live and therefore continued to undergo heavy treatments. In the last place, patients feared to get disappointed when their hope would not come true.

Conclusion: Hope can be a burden for palliative care patients and it is important for professionals to recognize these burdens in order to communicate about them. Future research could contribute to the development of strategies that help to relieve the burdens of hope.

Funding: ZonMw (The Netherlands Organisation for Health Research and Development)
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Aims: To identify best practice about how palliative and end of life (P&EoLC) research outputs should be presented to key stakeholders [clinicians, managers and service users].

Methods: We conducted 3 consultation workshops with CECo: 2 with patients/carers, 1 with clinicians/managers about how P&EoLC research results should be presented. Prior to workshops participants were sent P&EoLC research overviews aimed at the public. Clinicians/managers were also sent journal abstracts. Following discussion, nominal group techniques were used to produce recommendations for how research should be presented which were rated. Narrative comments were collected.

Results: Service user workshops comprised 18 participants making 41 recommendations. There was consensus that clarity of information and use of lay language was most important. Also more than primary endpoints should be given; include quality of life and a description of ‘what it was like to be on a study’. Users wanted independent indicators of quality such as a star rating system. Links to more information or help were needed as results could be upsetting. Despite lengthy discussion no consensus was reached on whether there should be explicit reference to P&EoLC.

Clinician/manager workshops comprised 12 participants making 19 recommendations. The main recommendation was the need to define what terms mean: end of life, palliative care, advanced care. More direct information about clinical and financial implications of research should be available. They wanted abstracts to be more accessible and readable.

Conclusions: Researchers need to be aware of numerous audiences when preparing research outputs. Increasingly lay people access research findings themselves via the internet, highlighting the need for clear and relevant research reports. Clinicians want reports that show both clinical and financial implications for practice. No consensus could be reached on use of terminology, replicating the EAPC 2009 position paper.

Abstract number: P199
Abstract type: Poster

MORECare Research Methods Guidance Development: Recommendations for Health Economic Evaluation in Palliative and End of Life Care Research

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Aims: To identify agreed best practice for health economic evaluation in palliative and end of life (P&EoLC) research.

Methods: We used the MORECare Transparent Expert Consultation approach to conduct consultation workshops with experts in health economics in P&EoLC research. Prior to workshops participants were sent overviews of pertinent issues in health economics in P&EoLC. Following workshop presentations and discussion, nominal group techniques were used to produce candidate recommendations. These were subsequently rated online by participating experts. Descriptive statistics were used to permit analysis of consensus and rated importance. Narrative comments were collated.

Results: The workshop comprised 28 participants making 27 recommendations. The top three recommendations were:
1. The need to develop robust methods for assessing outcomes which take into account preferences and the way these change over time.
2. Researchers should give consideration to the implications of decisions on the equitable distribution of care.
3. Costing should be from the societal perspective and as well as statutory services include costs of other formal care (e.g. hospices and third sector) and informal care unless a clear rationale for using a different perspective is provided.

The main area which failed to reach consensus were on the use of Quality Adjusted Life Years (QALYs) and whether individual opportunity costs should be used to measure the costs of informal care.

Conclusions: When designing studies in P&EoLC it is recommended that outcome measures are responsive over time and costings should come from a societal perspective taking into account the equitable distribution of care. More research is needed given the lack of consensus in this area so that future recommendations can be made.

Abstract number: P200
Abstract type: Poster

Gender Sensitive Participatory Research in Palliative Care with Older People

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Aims: The social category “gender” still needs more attention in doing research in palliative care. Especially participatory research with older people has to be aware
of gender effects on different levels. The aim of this paper therefor is to highlight the most important gender issues from a methodological perspective.

Methods: A metaanalyses of two qualitative research projects in palliative care on “ethical decisions in nursing homes” and “gender in long term care settings” has been undertaken. Reflections on the interview settings (male-male; male-female; female-female) as well as on group discussions and structural dimensions (number of participants at different hierarchical levels) have been carried out. Literature analyses questions or support the theoretical insights and give additional perspectives.

Results: Thinking and discussing about the face to face interview situations a “doing gender while doing research” effect can be supposed. A hypothesis can be formulated that themes emerge in a male-male communication differ from those that are talked about in female-female or male-female settings. In group discussions with professionals it turned out that within the context of elderly care there is a overwhelming high percentage of female participation. Male participation, especially when “gender” as an issue is discussed needs special attention. On structural level the question of “female organisation culture” as well as effects on leadership are central findings.

Conclusion: Gender sensitive participatory research has to acknowledge effects on individual, relational and structural level. Gender competences that include knowledge, emotional and cognitive reflexivity and gender sensitive behaviour are important for doing participatory research in palliative care with older people. Designing a research project therefor has to be aware of the gender effects that can come with certain social settings, interactions and organisational structures.

Abstract number: P201
Abstract type: Poster

Feasibility Study of the Sheffield Profile for Assessment and Referral for Care (SPARC): A Holistic Needs Questionnaire

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Background: SPARC is a multidimensional holistic screening tool which provides a profile of needs (i.e. physical, psychological, social, spiritual) to identify patients who may benefit from additional supportive or palliative care, regardless of diagnosis or stage of disease.

Aim(s): A feasibility study (randomised controlled trial) is being undertaken to establish whether using SPARC improves care (impact on quality of life, interventions, consultations, and referrals within supportive and palliative care), and to compare experience between patient groups.

Method(s): The study is carried out within in-patients, out-patients, day care and in community settings, and is developed, piloted, evaluated, reported and implemented in accordance with the Medical Research Council framework for developing and evaluating complex interventions. Patients are randomised to receive SPARC at baseline or after a period of two weeks (waiting list control). Care continues as normal; SPARC responses are communicated to the care team to ensure identified needs are addressed. Participants are asked to complete three short research questionnaires as part of the study, repeated after two, four and six weeks. A sub-group of participants were invited to participate in interviews.

Results: In the first six months of data collection, 318 patients were invited to take part, 100 patients have consented (31.4% response rate). The number of completed questionnaires returned at the following time points are as follows: baseline: n=82; 2 weeks: n=65; 4 weeks: n=51; and 6 weeks: n=37. Sixteen patients have been interviewed. Methodological issues will be presented at the conference.

Conclusion(s): Data generated from this feasibility study will guide the development of a further, larger definitive multicentre study to define the clinical utility of SPARC.

Funders: Funded by Macmillan Cancer Support.

Abstract number: P202
Abstract type: Poster

A Conceptual Model of Spirituality in Palliative Care

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Spirituality has emerged as a distinctive subject within palliative care practice and literature but research to date is relatively undeveloped in this field. A critical review of research into the spiritual needs of patients in palliative care (undertaken by the authors) reported that many studies are limited by the methodologies deployed and the unexamined assumptions upon which the research is based. For example few offered reflexive accounts of how they were approaching the subject, and the concept of spirituality employed in these studies generally went without much critical commentary.
It is evident that the research literature is typically founded on implied theory about spirituality and unstated or unquestioned assumptions. We argue therefore that research in this field is missing an important methodological step in the inductive cycle by failing to articulate explicit theory or identify critical concepts. We propose addressing this gap through constructing a conceptual model of spirituality. Drawing from a range of disciplines including sociology, health psychology and pastoral theology, we present a model that provides a systematic way of illustrating the essential properties, functions and relationships of how spirituality operates in the lives of palliative care patients.

If the model bears a reasonable resemblance to reality then spirituality is a multi-faceted construct that forms part of a dynamic intra-personal, inter-personal and social system. This suggests that a patient’s spirituality is not simply an additional attribute but an indivisible and interactive property of the person. The model also provides the conceptual apparatus and mechanisms that can underpin the development of both research and effective clinical practice. Following the presentation of the inductive cycle of model building we conclude by outlining the deductive cycle that we propose to test out the formulated model, identify anomalies and further refine it.

Abstract number: P203
Abstract type: Poster

Challenges Encountered during the First Non Sponsored Palliative Care Multicenter National Study in Switzerland

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Introduction: Research, especially in a palliative care (PC) setting, is quite difficult. The population studied is fragile and vulnerable with a limited prognosis (1). Multicenter studies could be a solution to progress in PC and therefore offer to these patients evidenced based medicine as well (2). A research study about advance directives, initiated in Geneva was afterwards transformed into a multicenter national study covering all three speaking regions with the support of the Swiss Academy Medical Sciences. In order to reveal the specific difficulties we have questioned the 11 national study covering all three speaking regions with the 11 research centers that were initially asked to participate in the study.

Method: Part of the regular evaluation included a questionnaire sent through E-mail to each main researcher of the 11 centers contacted in Switzerland. The questionnaire included ten sections covering varying subjects, which could be responsible for decline in research participation or delay in progress. All questions, except for those about difficulties related to patients and to personal convictions, were answered through a 4-level Likert-scale.

Results: The global participation rate to our questionnaire was 64%. We didn’t find a single main difficulty. However, there is a 66% agreement on having difficulties in finding staff for research, mainly because in Switzerland most of the research is done on a voluntary basis without extra finance or time attributed. However, we received a financial support by a non-profit organization. In total 118 patients are included so far. Two research groups, initially positive with participation, left the research group before including patients.

Conclusion: This multicenter study revealed to be quite a difficult task to realize. The willingness of the main researcher is present, but often retained by organizational problems, difficulties to find staff or due to the cultural background of the population.

Abstract number: P204
Abstract type: Poster

What Are the Challenges in Interdisciplinary Research? A Work of the “Latin” Platform of Research in Palliative and End-of-Life Care

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Introduction and aim: The features of interdisciplinary teams are well understood in current palliative care clinical practice. However there is little known on the challenges of interdisciplinarity in palliative care research. Since 2 years, researchers from almost 10 disciplines of the Italian and French part of Switzerland meet at regular intervals with the aim to develop research partnerships, disseminate research findings and collaborative research. The aim of this work is to identify the main challenges related to interdisciplinarity encountered by the platform members during these 2 years, also in particular in the context of a call for end-of-life research by the Swiss National Found.

Method: First, researchers of the platform, present during a meeting, were interrogated with an open question type-
written on a blank sheet: “In your experience what are the challenges in interdisciplinary research?”. The sheets were collected anonymously. These results will be elaborate during a large scientific meeting organized in January 2012.

**Preliminary results of the first part:** One category encompasses the items based on the fact that the knowledge of the disciplines is based on different concepts, methods but also skills. The lack of a common language, terminology and culture across different disciplines is underlined, as well as a lack of recognition of respective disciplines especially in the area of qualitative research. Another category encompasses the organisation of the daily clinical work as well as the problems of distinct hierarchies. The priority is given to clinical work with an important lack of time for research. Finally in some context, the lack of interest and expertise is underlined.

**Conclusion:** These results encourage us to continue the meetings of the research platform to better understand the core principles and concepts of each contributing discipline and to develop a shared vision that can be used across disciplines.

**Abstract number:** P205
**Abstract type:** Poster

**Involving Children in Palliative Care Research**

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**Aims:** In conducting research with children with life-limiting conditions, there has been reliance on the notion of competence. Different researchers have afforded different views and experiences of capacity. The current paper reports on our own experiences of involving children in palliative care research. We aimed to explore the lived experiences of children with life-limiting conditions and debate the associated developmental, ethical and methodological challenges.

**Methods:** Children with life-limiting conditions were involved in the study. To a degree, we ignored chronological age in our research design and instead considered how each child was able to communicate and show appreciation of their life circumstances. An interpretive phenomenological method was used, as this was viewed the most suitable for exploring the lived experiences (and total views) of children.

**Results:** All participants, including a child of just five years of age were very aware of their difference and of their illness and potential outcomes. Our research questions afforded us flexibility and assisted us in achieving a depth of response around living with life-limiting illness. Our questioning routes were exploratory in nature but we were also open to deviate in response to the questioning or actions of the children.

**Conclusions:** A ‘one rule fits all’ attitude does not work when considering the developmental capabilities and competencies of children with life-limiting conditions and their ability to participate in research. Patterns of understanding in children are fluid; individual experiences, environment, intellectual capacities, emotional profiles, ethnic, cultural and religious backgrounds - all contribute to how and when a child comes to understand the meanings of their illness. In general, what developmental theories and policies that have grown out of them, fail to acknowledge, is the impact of life events on development, including life-limiting illness itself.

**Abstract number:** P206
**Abstract type:** Poster

**Challenging Self-theory: The Unforeseen Outcomes of Conducting Research within One’s Own Area of Clinical Practice**

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**Background:** Research questions are often identified within the clinical environment by people closely involved with care delivery. Health professionals are increasingly encouraged to develop research skills, and contribute in all stages of the research process. This paper is based upon my experiences as a District Nurse and PhD candidate, who is undertaking qualitative research into the palliative and supportive care experiences of people affected by advanced disease.

**Aims:** To explore the experience of undertaking research within one’s own area of clinical practice, reflecting on unanticipated outcomes of the research process.

**Methods:** By drawing upon exerts from the research diary that was maintained through-out the research process, I personally reflect on three areas of significance. Firstly, what are the unanticipated outcomes of undertaking research? Secondly, how have these outcomes impacted upon my experience of undertaking research? Finally, how have these outcomes influenced my clinical practice?

**Findings:** The process of undertaking qualitative research can challenge health professionals to question their own clinical practice. Becoming a reflexive researcher requires stringent assessment of one’s own bias towards the topic of investigation. When this topic is closely aligned to clinical areas of responsibility and care provision, personal beliefs can be challenged as prior assumptions are questioned. This can be an uncomfortable process but one that has advantages for both research and clinical practice outcomes.

**Conclusion:** Research in palliative and supportive care can provide unforeseen personal challenges. Good clinical and research supervision is essential to support clinical researchers’ throughout the research process.
Developing and Evaluating a Hospital2Home Palliative Care Service for Patients with Advanced Progressive Idiopathic Fibrotic Interstitial Lung Disease: Phase 0-II

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**Background:** Work is needed to identify and meet needs of patients dying from non-malignant diseases such as Progressive Idiopathic Fibrotic Interstitial Lung Disease (PIF-ILD). We report our protocol for the development and evaluation of a case conference model of care and evidenced based guidelines (collectively termed Hospital2Home-H2H). At the case conference involving the patient, their carer and members of the multi-disciplinary team, the guidelines will be distributed and a care plan specific to the patient developed. Each health professional will be aware of their responsibility and duties. We will look at whether this results in better symptom control and quality of life for the patient and their carer whilst being cost-effective.

**Aim:** To develop a H2H intervention for patients with severe PIF-ILD and to evaluate it in terms of processes and outcomes.

**Methods:** This project uses a sequential mixed methods design and the Medical Research Council (MRC) Framework for the Evaluation of Complex Interventions.

**Results:** We have conducted a systematic review (Phase O) and qualitative interviews (phase I) with patients, carers and health professionals to ascertain views of current needs of patients dying from non-malignant diseases. We are currently recruiting to a fast-track RCT to test the effectiveness of the H2H intervention (phase II). Inclusion criteria for the RCT: inpatients and outpatients with PIF-ILD in the last year of life. Consenting patients are randomised to either receive the intervention immediately (fast-track) or after a 4-week wait (standard practice). Interviews are conducted at baseline, 4 and 8 weeks. In addition qualitative interviews will be conducted.

**Discussion:** The MRC Framework and the sequential mixed methods design have been helpful in the design and evaluation of the intervention. The research will provide valuable information on the effects of this end of life intervention on PIF-ILD patients and their carers whilst assessing it’s cost-effectiveness.
Distress and Identity Crisis at the End of Life, a Prospective Observational Study

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This research was intended to determine links between an identity crisis and psychological distress for patients at end of life. In 2009, Dr. Chochinov wrote that the appreciation of the nature of distress is the new challenge of palliative care. Currently, professionals understand this distress to be like psychological disorders which must be treated.

Methods: We conducted a retrospective, cohort and multicenter study in which 14 psychologists from French palliative care teams participated. During one year, they used a booklet to analyze throughout their interviews the psychological effect of the lethal illness. It was a hetero assessment after interviews with an analogical scale of 35 items relating to distress, sense of identity or defense mechanisms. Patients with a terminal prognosis were receiving palliative care in a hospital or community setting (hospice or home) and requesting psychological support. A second control group of 12 psychologists used the booklet with 100 patients. Statistical analysis used stata corps.

Results: 237 patients aged 67 years (39-102) requesting psychological support were included. 801 interviews were carried. Distress levels was important (>4/10) and highly correlated (p< 0,5) with identity crisis and decreasing physical capacity/emotion rupture of feelings of unit and self-esteem. There was no correlation with age, gender or social support system. The longitudinal analysis demonstrated a reduction and identity resilience near death. Physical losses were less important in these interviews. Distress made sense in the psychological functioning of patients and could be reduced through the therapeutic relationship. Psychologists report that when experiencing feelings of helplessness there is a correlation with distress; however dreaming is correlated with the well-being of patients. From this study, we can already conclude that distress is related to the importance of ruptures of identity. Brief psychological therapy is efficient.
Background: Many nursing home residents with dementia may benefit from palliative care. However, difficulties in predicting death and failure to recognize dementia as a terminal disease may impede early planning and provision of palliative care.

Aim: To assess to what extent palliative care is being planned in residents with dementia, and factors associated with early or later planning of palliative care.

Design: Prospective and after-death data collection using written questionnaires between January 2007 and July 2010, and survival up to July 2011.

Setting: Nursing homes across the Netherlands.

Participants: Residents with dementia (n=372), their physicians and family.

Measurements: Resident care goals from admission until death or conclusion of data collection, and factors potentially related to these care goals.

Results: Preliminary analyses show that shortly after admission, for 57% of residents with dementia palliative care was the most important care goal, for other residents the most important care goals were maintaining or improving of functioning (20%), prolonging life (1%) or another care goal (3%). For 19% of the residents no care goal was determined yet. On the day of death, the care goal was palliative for 89% of the residents. An early palliative care goal was associated with the physicians' opinion that the resident was closer to the end of her/his life (p = 0.004). Residents with family who were satisfied with family-physician communication more often had an early palliative care goal. Early setting of a palliative care goal was associated with perceived prognosis and family-physician communication.

Conclusion: At admission over half of resident had a palliative care goal. Early setting of a palliative care goal was associated with perceived prognosis and family satisfaction with family-physician communication.

Abstract number: P212
Abstract type: Poster

Age-based Disparities in End-of-Life Decisions in Belgium

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Background & aims: A growing body of scientific research is suggesting that end-of-life care and decision making may differ between age groups, and that elderly patients may be most vulnerable to exclusion of due care and questionable practices at the end of life. This study investigates age-related disparities in the rate of end-of-life decisions (ELDs) and the preceding decision making process in Flanders, Belgium 2007. Comparing with data from an identical survey in 1998 we also study the evolution of end-of-life decisions among different age groups.

Method: We performed a post-mortem survey among physicians certifying a large representative sample (n=6927) of death certificates. Response rate was 58.4%.

Results: While the rates of non-treatment decisions (NTD) and administration of life-ending drugs without explicit request (LAWER) did not differ between age groups, those of intensified alleviation of pain and symptoms (APS) and euthanasia/assisted suicide (EAS), as well as the proportion of euthanasia requests granted, were bivariately and negatively associated with patient age. Multivariate analysis showed no significant effects of age on ELD rates. Older patients were less often included in decision making for APS and deemed incompetent more often than younger patients. Comparison with 1998 showed a decrease in the rate of LAWER in all age groups except in the 80+ age group where the rate was stagnant.

Conclusion: Age is not a determining factor in the rate of end-of-life decisions, but all the more so in decision making as patient inclusion rates decrease with old age. Our results suggest the need for a focus of advance care planning initiatives on elderly (non-cancer) patients. The oldest patients are more at risk of unethical practice at the end of life.

Abstract number: P213
Abstract type: Poster

Locus of Control and Cognitive Functioning in Elderly Cancer Patients’ Depressive Symptoms

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Research aims: This study evaluated depression, sense of control, and cognitive functioning for identifying their associations as well as the predictive power of sense of control and cognitive functioning in depression in elderly cancer patients.

Methods: Participants were 86 cancer patients referred to a palliative care unit. Participants completed the short version of the Geriatric Depression Scale (GDS), the The Cancer Locus of Control (CLOC) scale, and the The Mini Mental State Examination (MMSE).

Results: Significant correlations were found between metastasis and chemotherapy with the GDS-15 scales
of “feelings of helplessness and fear for the future” and “social isolation and social functioning”, respectively. Significant associations were found between “course of illness” and “cause of illness” with all GDS-15 scales with r ranging from -0.186 to 0.514. “Course of illness”, “cause of illness”, MMSE, and metastasis provided the strongest prediction of depression.

Conclusions: The results suggest that elderly cancer patients’ sense of control over the course of illness, the cause of illness, their cognitive functioning, and the presence of metastasis, predicts the presence of depressive symptomatology.

References:

Abstract number: P215
Abstract type: Poster

Older Patients with Advanced Heart Failure at the End of Life: Contrasting Cases to Explore Communication about Illness and Prognosis

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Background: Heart failure is one of the leading causes of death and can result in high palliative care needs. Recently, in a project on health care for older patients with advanced heart failure in Germany, we found the need to improve information and communication about illness and prognosis [1]. The aim of this study was to further investigate these needs.

Methods: Contrasting two cases - both women, 86 and 95 years old, heart failure NYHA III/IV - from the sample of 25 patients [1] by means of their social support: one patient with strong social support (5 close relatives reliably looking after her), and one with weak social support (a more distant relative and a neighbour). 4 qualitative interviews, covering a period of 9 months, were carried out with each patient (total of 8 interviews). The interviews were analysed using qualitative content analysis.

Results: Both patients are poorly informed concerning the illness and prognosis of heart failure but deal with their own illness in a different way: The patient receiving strong social support relies on her relatives to take care of any important issues. By contrast, the patient with the weaker support displaces her problems of dealing with the illness to the family doctor but struggles with confiding it. Actively seeking information about the illness is limited. The patients’ thoughts concerning death are related to experiences with the death of beloved ones rather than their own finiteness. Their focus is more on organisational issues (e.g. arranging the funeral) than on emotional aspects.

Conclusion: Open discussion of end-of-life issues is difficult in older patients with advanced heart failure, especially if social support is lacking. Closely involved health professionals such as the family doctor should be aware of patient related barriers and actively address end-of-life issues.


Funding: Robert Bosch Foundation

Abstract number: P216
Abstract type: Poster

Study Protocol for a Cluster Randomized Trial to Evaluate the Influence of the Liverpool Care Pathway on End-of-Life Care in Acute Geriatric Hospital Wards in Flanders

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Background: To improve the quality of end-of-life care, the Liverpool Care Pathway for the Dying Patient (LCP) was developed in the UK. Studies have shown that the LCP contributes to cancer patients’ quality of life in the dying phase. Few randomized controlled trials have, however, been conducted to evaluate its effect and it is also unknown what effects can be achieved in patients dying in acute geriatric hospital wards.
**Objectives:** To study the effect of the LCP in acute geriatric hospital wards in Flanders on: (1) the quality of life of the patients during the last three days of life, (2) the content of care, (3) communication, and (4) the level of bereavement of relatives.

**Methods/design:** A pre-post intervention study with control groups will be conducted. Ten acute geriatric hospital wards will be randomized to receive the intervention (implementation of the LCP) or no intervention (control group). After randomization, we will conduct a one-year baseline study in both the intervention and control wards, during which care will be provided as usual. For each deceased patient, a questionnaire will be filled in by a nurse, a physician and a relative. Subsequently, the LCP will be implemented in the intervention wards. In the control wards care will be provided as usual. Following implementation, we will conduct a one-year intervention study in all participating wards, using the same questionnaire as in the baseline study. Measurements on patients dying during the baseline and intervention period and in the intervention and control wards will be compared to assess the effect of the LCP.

**Discussion:** This will be the first randomized controlled trial in Belgium that will evaluate the effect of the LCP on patients’ quality of life and care during the last three days of life in acute geriatric hospital wards. The results will enable us to evaluate whether use of the LCP has positive effects in this patient population.

**Funding source:** IWT-SBO

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**Abstract number:** P218

**Abstract type:** Poster

**The Challenge of Maintaining Personal Dignity in the Nursing Home: A Qualitative Interview Study among Dutch Nursing Home Residents**

**Oosterveld-Vlug M.G.¹, Pasman H.R.W.¹, van Gennip I.E.¹, Muller M.T.², Willems D.L.³, Onwuteaka-Philipsen B.D.¹**

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**Context:** Nursing home residents are exposed to diverse factors which may be associated with loss of personal dignity: they experience functional incapacity, are heavily reliant on staff and live in an unfamiliar environment. To help this vulnerable group withstanding these potential

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**Abstract number:** P217

**Abstract type:** Poster

**End of Life Care for Patients with Advanced Heart Failure - Development of the Brent Integrated Model**

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The aim of the project was to develop an integrated approach to the assessment & care of patients with advanced heart failure (HF) in Brent, to ensure better identification, palliation of needs & choices at the end of life.

This NHS Improvement project was managed through regular meetings of a stakeholder group.

Retrospective audit of 26 deceased patients known to community HF nurses identified that the majority of patients had multiple admissions in the last year of life. There were 81 admissions totalling 879 bed days. There were a further 40 attendances & 3 deaths in A&E.

Yet only four patients had end of life discussions or a documented preferred place of care. 5 patients received input from specialist palliative care. None accessed hospice services.

A Heart Failure “Cause for Concern” trigger tool was created for use by community HF nurses to identify patients with advanced disease for discussion at a newly established Advanced Heart Failure Multidisciplinary forum. This meeting lead by a cardiologist modified cardiology management & also identified those who would benefit from shared care & a palliative approach. Via written correspondence, outcomes of the MDT were shared with the GP & all professionals involved.

Established tools (eg PACA) were adopted & a new palliative management tool developed for community HF nurses to trigger joint work with palliative care services.

An end of life care folder containing relevant information was left in the patient’s house & its contents shared with the London Ambulance Service (LAS) & out of hours providers.

Work with LAS resulted in a protocol for palliative management of patients.

The re-audit of 19 patients showed reduced hospital use and death rates in hospital and increased use of palliative care services and planning conversations.

**Summary:** Patients with Advanced HF benefited from the partnership approach, creation of an clarified shared pathway, a new MDT forum, clear communication & adoption of new & modified tools.
threats and to protect them from feeling undignified, it is important to investigate this concept from the nursing home residents’ perspective.

**Aims:** To gain insight in the way Dutch nursing home residents experience their dignity and the factors that hamper or preserve this.

**Methods:** Qualitative in-depth interviews were used to explore the views of 30 recently admitted nursing home residents on the somatic wards of 4 nursing homes in The Netherlands.

**Results:** As in the general patient population, illness related factors were the starting point of a process which could affect the resident’s dignity, by threatening aspects of the individual self as well as aspects of a resident’s social world. However, many nursing home residents were able to maintain a certain level of dignity, despite all threats. Living in a nursing home was, in itself, not seen as a reason for feeling less dignified, but merely as an inevitable consequence of functional incapacity. Nevertheless, waiting for help, being patronised by nurses and not receiving enough attention could, among others, hamper personal dignity. On the other hand, aspects of good professional care (e.g. being treated with respect, being taken seriously and receiving good quality care) were found to protect dignity.

**Conclusions:** Contrary to the general view in society that nursing home care can only take away one’s personal dignity, good professional care can preserve dignity as well. To strengthen the preservative effect of nursing home care on residents’ dignity, more attention should be given to the way staff addresses and treats nursing home residents.

**Main source of funding:** The Netherlands Organisation for Scientific Research (NWO).

**Abstract number:** P220
**Abstract type:** Poster

**The Relevance of Hospice and Palliative Care in Nursing Homes**

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**Background:** Many residents of nursing homes suffer from multiple terminal illnesses with phases of progressive deterioration, many suffer from dementia. An expertise in hospice and palliative care is highly required on all levels.

**Aims/questions:** One important aim is to change the culture in the nursing home. The main questions are:
* What are the core themes that have to be taken into account?
* Who are the target groups?
* What problems have to be solved?

**Methods:** Guidelines for quality of palliative care in nursing homes were defined. A model architecture for the integration and a description of the organisational developement process were created. A curriculum in Palliative Geriatrics and workshops to train the trainer were developed. In 37 model homes the integration of hospice and palliative care was/is realized. 15 are still going on. A qualitative and a qualitative evaluation was made in the first 12 model homes.

**Results:**
* A successful implementation requires a combination of organisational development and ongoing training.
* The training methods of the curriculum have to meet the diverse needs of people with different educational backgrounds and encourage and request the learners’ activity.
* A successful integration improves the daily communication both internal and outbound, creates the carers’ awareness, confidence and courage, strengthens the multidisciplinary team, supports in dealing with difficult ethical issues and improves the residents’ quality of life equally to their families’ and loved ones’ quality of life.

**Conclusions:** It is important to develop guidelines, a model architecture of an organisational development process, a curriculum and training in palliative geriatrics to improve quality of care for the elderly, to support their beloved ones and to enhance workplace health promotion. In the same way it is essential to have an advisory board with all relevant policymakers. Additionally it is necessary to cultivate the networking.

**Abstract number:** P221
**Abstract type:** Poster

**Routine Use of Fentanyl Buccal Tablets for Breakthrough Cancer Pain in Germany/Austria - Results of a Non-interventional Study as Part of a European Risk Management Plan**

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**Aims:** Breakthrough cancer pain (BTcP) is a transitory exacerbation of pain that occurs on a background of otherwise controlled persistent cancer pain. A majority of cancer patients (51-95%) suffer from BTcP and studies have indicated that BTcP is associated with significant patient morbidity (decreased functioning, depression, distress…). Fentanyl buccal tablet (FBT) is a new opioid formulation that provides rapid-onset analgesia for the treatment of BTcP in patients already receiving opioid maintenance therapy. As part of a European risk management plan a non-interventional study (NIS) was conducted in Germany and Austria to evaluate tolerability and efficacy of routine use of FBT.
Methods: After a patient’s physician decided to treat BTcP with FBT, the patients’ pain management was systematically documented for up to 8 weeks. BTcP treatment of 353 patients treated between March 2009 and August 2010 has been analyzed.

Results: The results confirmed clinical trial data regarding efficacy and tolerability of FBT. Most patients reported sufficient pain relief within 10 minutes after application and FBT reduced the median pain intensity during BTcP episodes. More than 70% of the patients were satisfied with FBT treatment and rated the ease of FBT administration as “easy” or “very easy”. Adverse drug reactions (ADRs) were reported in 3 patients with a total of 5 events; all but one (sepsis) of these were non-serious and expected according to the European SmPC.

Conclusions: Therefore, this NIS provided a representative cross-sectional study of the routine use of FBT in Germany/Austria that confirmed efficacy and tolerability of FBT at managing BTcP.

Abstract number: P222
Abstract type: Poster

Providing Guidance for Palliative Care of Older People in the Community

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Aims: In Australia, as in Europe, the proportion of the population over 65, and over 85, is increasing with most living in the community - in their homes, in retirement villages or with friends and relatives. Older people living in the community who have a progressive, life-limiting illness or frailty will influence the demand for, and delivery of, palliative care. The purpose of this project was to develop evidence based guidelines for a palliative approach for aged care in a community setting.

Methods: The development of these guidelines was based upon a national consultation with representatives of key stakeholder groups and the public. This consultation, along with advice from the project’s reference group, determined the scope of needed guidance and the document’s topic areas. Five specific systematic reviews as well as a comprehensive literature review formed the evidence base. The guidelines were developed in accordance with the (Australian) National Health and Medical Research Council’s guideline development processes and were approved in November 2010.

Results: Guidance is provided on ten main areas - a palliative approach to care; a palliative approach in the community; family carers; advance health care planning; physical symptoms; psychosocial care; spiritual support; a palliative approach for Aboriginal and Torres Strait Islander people; a palliative approach for those from diverse cultural groups; and people with special needs and perspectives. The guidance comprises 13 guidelines from the systematic reviews and 159 good practice points deriving from the comprehensive literature review.

Conclusions: These guidelines draw upon a growing body of research relating to a palliative approach to care for older people in the community and will assist those providing care in this setting.

Funding: The Guidelines for a Palliative Approach for Aged Care in the Community Setting were funded by the Australian Government Department of Health and Ageing.
Conclusions: As signified by my allied research findings, there is an element of mutual protectiveness and a truth-telling hesitance complicated in the dyadic relationship of parent and child. In this respect, dignity therapy would be a very worthwhile intervention.

Abstract number: P224
Abstract type: Poster

Paediatric Palliative Care - A Unique Way of Caring

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Background: Paediatric palliative care is an integrated approach to ensure quality of life for children and adolescents with an unpredictable but probably short life expectancy. Family involvement is very important and parents are involved in crucial decisions concerning their child and the whole family. An interdisciplinary team aims to give an active total care of the child’s body, mind and spirit and recognizes complementary methods to be important. A year has passed since the first palliative care unit for children and adolescents in Scandinavia, Lilla Erstagården, opened in Stockholm, Ersta Hospital. The first therapy dog for children - a labradoodle named Livia - works here Monday to Friday. The aim was to evaluate parents’ views by asking 26 questions about the stay and the care given.

Methods: Questionnaires were given to parents some weeks after their stay at Lilla Erstagården, where their child was cared for, both in the end-of-life and in respite care.

Results: In this presentation we will concentrate on two important questions - the therapy dog and being together as a family.

It appears that the dog contribute to a more joyful, home-like and “normal” atmosphere. The parents put forward that the dog brought a pause from the stressful life situation. Having the opportunity to be the whole family together was important for the dying child, for the parents and for the siblings. The environment, both atmosphere and the place seemed to promote this.

Conclusion: Having a therapy dog and inviting the whole family create environment helping the grieving parents. It is important to recognize the child for the child itself even or especially if the child is dying. Finally we emphasize that it is vital to give the family a possibility to be a family and the child to be a part of the family.

Abstract number: P225
Abstract type: Poster

Use of a Common Data Set to Explore the Distribution of Children with Palliative Care Needs in the West Midlands of the UK

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This paper presents part of a larger study aimed to identify and map children with life-limiting conditions known to health and voluntary sector services in the West Midlands of the UK and to investigate gaps in provision, clustering of need and association with deprivation. Prevalence estimates from local studies (around 16 per 10,000 children) indicate 2000 children in the region will have supportive and palliative care needs.

Patient sample: 20 statutory health and voluntary sector services provided a minimal data set of children with life limiting conditions known to them. The common data set included: date of birth, gender, ethnicity, primary diagnosis and post code sector.

Methods: Diagnoses were categorised using ICD 10. Data are presented using descriptive statistics and geographical information systems.

Results: Preliminary analysis indicates half of the children had diseases of the nervous system (ICD 10 code G), 20% had congenital malformations and chromosomal abnormalities (code Q). Other main categories were: metabolic conditions (code E), conditions originating in the perinatal period (code P), oncology (code C), digestive system (code K), mental and behavioural (Rett syndrome) (code F ). The largest single diagnosis is Duchenne Muscular Dystrophy (12%) (code G71.0).

Conclusion: The ICD10 classification splits children with similar clinical and social needs across different categories whilst some with specific and different needs are categorized together. The information value for palliative care service planning is limited. Because the majority of children have conditions of the CNS, categories relating to trajectories of the disease and social needs of the children and young people would be more helpful for understanding the population and service needs, and for regional and international comparison.

Abstract number: P226
Abstract type: Poster

Place of Care at the End-of-Life and Dying: Portuguese Preferences

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Aim:
• To identify the Portuguese preferences about the local of care at the en-of-life and the place of death;
• To identify some factors which can affect those preferences
Abstracts

Methods: 1288 people (18-93 years old), from all country regions, were asked about how often they thought about death and what would be their preferences about these issues; also, the main reasons to those preferences were asked.

Results:
- One third, often or always thought on death; 22.3% sometimes; 25% rarely and 18.4% never; The elderly think more on death than the young people;
- 61.7% want to be cared at home, at the end-of-life; 14.25% at the nursing home; 15% at the hospital and 9% at the palliative care unit;
- 65% want to die at home; 9% at the nursing home; 18% at the hospital and 8% at the palliative care unit
- The main factors influencing the preferences are: age, education level and country region;
- The main reasons they had chosen the home are: the possibility to have near them their friends/family/the loved ones and to not to be alone; for nursing home: to avoid being a burden to the family/friends, to have support for their needs and health care whenever necessary; for the hospital and palliative care unit: the support for their needs, health care whenever necessary, to be better cared at that phase of life and to avoid being a burden to family/friends

Conclusions:
- For the Portuguese to achieve a “good death” it is necessary to develop a network of palliative care resources, specially, home palliative care teams, which they must deliver health care 24h/day, in order to have the people at the end-of-life able to be cared and to die where they wish.
- It is important research why the subjects prefer more the hospital than the palliative care services.

Abstract number: P227
Abstract type: Poster

Dying in a Hematological Unit: Experiences Based on the Swedish Palliative Registry

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Aims: The Swedish Palliative Registry (SPR) highlight the period immediately before death at various care units in Sweden, with the primary aim to enable improvement of care in patients in their last phase of life. We here present the results from a specialized haematological unit with 20 beds after 18 months of registration.

Methods: From April 1st 2010 until September 30th 2011, all but 3 patients that died in our unit have been registered in the SPR. A questionnaire regarding different quality criteria during the last period of life were registered after death. Registration of information about the use of VAS in pain assessment and oral care started in 2011.

Results: During the period, 41 patients died whereof 3 patients unexpectedly. In addition, 12 patients died in the ICU and 2 patients died in another unit while formally being our patients. M/F ratio was 35/20. The average age for all patients was 67 years (range 19-87), for ICU patients it was 50 years (20-71). All but one died of haematological malignancies. The results, from 35 patients that died expectedly are presented in table 1.

Table 1. Data recorded from our unit in the Swedish Palliative Registry

<table>
<thead>
<tr>
<th>Quality indicator</th>
<th>Aim</th>
<th>Result: N=35</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physicians information to the patient/next-of-kin</td>
<td>100</td>
<td>68.5/85.7</td>
</tr>
<tr>
<td>Dead without pressure ulcers</td>
<td>90</td>
<td>77.1</td>
</tr>
<tr>
<td>Another person in the room present at the time of death</td>
<td>90</td>
<td>94.2</td>
</tr>
<tr>
<td>Relieved from pain</td>
<td>100</td>
<td>74.2</td>
</tr>
<tr>
<td>Relieved from nausea</td>
<td>100</td>
<td>88.5</td>
</tr>
<tr>
<td>Relieved from anxiety</td>
<td>100</td>
<td>57.1</td>
</tr>
<tr>
<td>Relieved from wheezing</td>
<td>100</td>
<td>80.0</td>
</tr>
<tr>
<td>The patient died where he wanted to die</td>
<td>100</td>
<td>40.0</td>
</tr>
<tr>
<td>Oral care documented (from 2011)</td>
<td>100</td>
<td>52.6</td>
</tr>
</tbody>
</table>

The age of our patients at death is relatively low and a rather high proportion of our patients died in the ICU, reflecting that this is an acute medical unit. We did not assess any patients with VAS.

Conclusions: By using the SPR, we conclude that there is a large potential for improvement of the end-of-life care in our unit.

Source of funding: Sahlgrenska University Hospital

Abstract number: P228
Abstract type: Poster

Initiating Relevant Conversations about Advance Care Planning in a South African Context: A Qualitative Study

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Aims: To explore the following questions:
1. Have advance directives been applied in South Africa?
2. Do advance directives have a place in South African Health care?
1. Do advance directives have relevance in resource poor settings for users of rationed public health care?
2. What questions are appropriate when discussing advance directives?
3. What timing is appropriate for these discussions, who should initiate the discussions?

Methods:
1. Research ethics approval sought and granted by the research ethics committee of the Hospice and Palliative Care Association of South Africa.
2. The research tool used was the one slide project (an American tool used to facilitate end of life planning discussions).
3. Five focus group discussions were conducted, facilitated by the principal researcher (Janet Stanford Palliative care doctor at Knysna Sedgefield Hospice), assisted by Dale Sandberg (Psychology graduate). The discussions were recorded and transcribed.
4. Themes were grouped.
5. Adaptations of the one slide were made on the basis of the focus group discussions.

Results:
Themes which emerged from the focus groups were:
1. The difficulty of outlining wishes without specific scenarios
2. Resources and location of care
3. Trust
4. Capacity to implement an AD (not legally binding in SA, gender issues)
5. Stigma around opening up a discussion about death
6. Poor understanding of the distinction between a will and AD
7. The timing of an AD discussion.
Adaptations were made to the one slide based on the feedback from the focus groups.

Conclusion: There was great interest in the implementation of ADs in South Africa among all participants from a range of socioeconomic and cultural groups. Changes were made to the one slide based on the feedback. The logical next step in the research will be to seek the assistance of South African hospices to pilot the adapted AD.

Abstract number: P229
Abstract type: Poster

Defining End-of-Life Care from the Perspective of Nursing in Japan

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Introduction: End-of-Life Care(EoLC) was introduced in 1999. Despite increasing interests and urgent needs for quality EoLC, there is no exact definition of what is the interval referred to as end of life or what end-of-life care is.

Purpose: The purpose of this paper is to report our examination of terms related to EoLC and define end-of-life care from nursing perspectives.

Methods: A systematic search of electronic databases identified research-based nursing papers explicitly focused on “End-of-Life Care” and “Definition”. Thirty-seven papers published between January 1999 and October 2011 was collected from CINAHL, PubMed, and MEDLINE databases. It inquired including the definition which the public organization of WHO, National Cancer Institute at the National Institute of Health (NIH), NHS(UK), The Canadian Hospice Palliative Care Association (CHPCA), The European Association for Palliative Care (EAPC), Palliative Care Australia (PCA), and Japan in the world which leads the view of palliative care has proposed.

Results: We propose the definition of EoLC as “to assist persons who are facing imminent or distant death to have best quality of life possible till the end of their liferegardless their medical diagnosis, health conditions, or ages.” In this definition, the end of life is a discreet time period when a person is aware of end of the life, not a medically determined period of time before death. Regardless of health conditions, if a person reflects on his, her, or other’s life and has concerns about death and end of the life, this person, in a sense, is facing death and may benefit from care defined as EoLC.

Conclusions: This definition has potential to expand roles of nurses in EoLC from bedside direct care providers to educators and policy makers in their community to assure quality EoLC to all people. Because of our values and philosophy aligning well with EoLC, nurses have much to offer and lead to improve quality of EoLC.

Abstract number: P230
Abstract type: Poster

Lung Cancer Mortality in Salamanca during the Period 1998-2007

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Objective: The aim of this paper is to analyze mortality from lung cancer in the province of Salamanca during the period from January 1, 1998, and December 31, 2007, although a review of mortality trends the last three decades, then compare the results with the events in Spain and Europe in the same period. With this, we try to provide a better understanding of trends over the last ten years, of patients who die from cancer in our province.

Methods: We performed an epidemiological study, descriptive and ecological, of patients who died in the
province of Salamanca during the period from January 1, 1998 and December 31, 2007. Data on the total number of people who died in Salamanca on cancer disease between January 1, 1998 and December 31, 2007, including leading cause of death, age, year of death and sex were obtained from National Statistics Institute (INE). These data are based on official death certificates. We analyzed age-adjusted rates to the European population and truncated rates (35-65 years), separated into two five-year periods, 1998-2002 and 2003-2007, we analyzed the difference between five-year periods and the% growth.

**Results:** There is a decrease, both sexes and globally, in Salamanca (-13.55% in men, -9.03% in women and -13.08% global). By studying the truncated rates (35-65 years), age-standardized way, we see that there is only a decrease, both sexes as globally, in Salamanca (-15.25% in men, and -5.92% in women and -14.08% globally).

**Conclusions:** In our study, we show, in contrast to previous studies, a decrease in mortality rates from lung cancer, both overall and truncated, women in the province of Salamanca, with a decrease of 9% and 5 % respectively.

**Abstract number:** P231

**Abstract type:** Poster

**Is Breakthrough Cancer Pain (BTcP) in Elderly People Still Undertreated?**

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**Context:** The prevalence of cancer increases with age, and BTcP, frequent in cancer patients (75%), is still underrecognized and undertreated. In addition, age (>75) has been shown to be a predictive factor of inadequate analgesia (1).

**Patients and methods:** In a prospective, national, multicenter survey conducted from march to september 2010 in 45 centers treating painful cancer patients (oncology, palliative care and pain centers, public or private) practitioners evaluated during 1 week all patients with severe cancer pain requiring opioids. Prevalence, characteristics and predictors of BTcP including age have been assessed.

**Results:** There is a decrease, both sexes and globally, in Salamanca (-13.55% in men, -9.03% in women and -13.08% global). By studying the truncated rates (35-65 years), age-standardized way, we see that there is only a decrease, both sexes as globally, in Salamanca (-15.25% in men, and -5.92% in women and -14.08% globally).

**Conclusions:** In our study, we show, in contrast to previous studies, a decrease in mortality rates from lung cancer, both overall and truncated, women in the province of Salamanca, with a decrease of 9% and 5 % respectively.

**Abstract number:** P231

**Abstract type:** Poster

**Prevalence and Characteristics of Cancer-related Breakthrough Pain in a Heterogeneous Cancer Population in Norway**

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**Introduction:** Prevalence and characteristics of breakthrough pain (BTP) varies in different surveys. This might be due to between study differences in patient populations, classification of pain and assessment methodology used. The aims of the present study were to investigate the prevalence, characteristics and conditions associated with BTP in a heterogeneous cancer population.

**Material and methods:** A cross-sectional study of in- and outpatients (pts.) in three different hospitals was conducted. On predefined days, a questionnaire was distributed to all cancer pts. at each site containing demographic questions, the Brief Pain Inventory (BPI), and the Alberta Breakthrough Pain Assessment Tool for Cancer patients. Results from descriptive statistics and univariate analyses as well as findings form the literature decided what variables to include in multivariate logistic regression analysis.
**Results:** 454 cancer pts. were approached and 410 were eligible for inclusion (mean age 62 yrs, 52% female). 371 were included at Trondheim University Hospital, 21 at Aalesund hospital and 18 at Haugesund hospital. 19% had BTP (in-pts 28%, out-pts 15%). Pts. with BTP had a mean of 3.1 episodes of BTP a day, the BTP mean intensity was 6.8 (11-point numerical rating scale, NRS). BTP was more common for patients with higher intensity of persistent pain, among in-pts. and for pts. with poor performance status (PS). Pts. with BTP reported higher scores on the BPI interference items. In multivariate regression analysis BTP was associated with poor PS and higher persistent pain intensity.

**Conclusion:** The prevalence of BTP was low compared to other studies which have reported prevalence of BTP from 20% to 95%. The present observation may be related to the selection of patients, BTP definition and the assessment tools applied as well as the integration of palliative care into oncology at Trondheim University Hospital.

**Abstract number:** P233  
**Abstract type:** Poster  
**Choosing between Treatments: The Role of Indirect Treatment Comparisons and Network Meta-analysis in Healthcare Decision Making**  
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**Aim:** Clinicians make choices every day concerning the treatment options that are most effective and safe for their patients. This poster will introduce the concept and methods of network meta-analysis (NMA) and outline how NMA can support reimbursement decisions in clinical decision making.

**Methods:** In the face of competing treatment options, clinicians need to be well informed as to the efficacy and safety of the different treatments available. In order to decide which treatment to prescribe to patients, they consider the evidence from randomised controlled trials (RCTs). However, clinical trials are, generally, not designed in such a way that standard care is compared directly to other currently available treatments. The challenge for clinicians is how to proceed in the absence of this “head-to-head” data. NMA provides an answer to this challenge. Whilst traditional meta-analysis provides only pairwise comparisons, indirect treatment comparisons (ITC) or NMA allow you to synthesise the highest available evidence simultaneously, such that treatment effects of pairwise comparisons, so-called direct evidence and indirect evidence, are analysed simultaneously.

**Results:** The results of the different interventions in the included studies are combined using a Bayesian ITC or NMA technique. Outcomes of the analysis are presented as adjusted absolute values (e.g., % of patients responding to treatment or having an event), relative risks, odds ratios, and absolute treatment and relative treatment differences. In addition, the ITC or NMA allows probabilistic interpretation of uncertainty and ranking.

**Conclusion:** With many treatments available, ITC or NMA overcome the lack of data and are useful methods to inform clinical decision makers when selecting the most efficacious and safe treatment option available.

**Abstract number:** P234  
**Abstract type:** Poster  
**Pain and Quality of Life of Inpatients Admitted to a Comprehensive Cancer Center**  
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**Aim:** This prospective study aimed to describe a sample of inpatients admitted to departments of oncology and hematology.

**Methods:** A cross sectional study, in which 188 cancer inpatients were invited to participate during May and June 2011. Patients were assessed in seven wards in two rounds of five days. No patient was included twice. Inclusion criteria: Age ≥ 18 years. Exclusion criteria: absence at assessments or not able to complete the questionnaire. Assessments: sociodemographics, diagnoses, performance status (WHO scale), antineoplastic and supportive/palliative treatment, pain types, relief and intensity (Brief Pain Inventory) and quality of life (EORTC QLQ-C30, scale 0-100).

**Results:** 134 (71.3%) patients accepted to participate in the study (58.8% male, mean age=59.2y (SD=13.5), most frequent diagnoses were leukemia (27.6%) and lung cancer (14.2%)). 53.7% were admitted for treatment with curative...
intensity and 29.9% with palliative intent. Pain intensity in the last 24h was mild in 41.9%, moderate in 20.2% and severe in 1.6%. 72.7% had nociceptive and 38.2% neuropathic pain (n=55). Breakthrough pain in the last 24h (1-6 episodes) was reported by 27.6%. Pain relief in the last 24h (< 20% relief) was reported as very poor by 32%. The most frequently used analogesics were opioids (31.3%) and paracetamol (27.6%); adjuvant analogesics were used infrequently. Overall quality of life was considered poor or very poor in 49.6% (EORTC score < 50).

Conclusion: At a comprehensive cancer centre approximately one third of inpatients reported very poor pain relief and breakthrough pain in the last 24h. Furthermore, half of the inpatients reported poor quality of life. The use of adjuvant analogesics was sparse.

Abstract number: P235
Abstract type: Poster
Consumption of Strong Opioids for Palliative Care in Europe: The Influence of Country-level Characteristics
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Aims: Effective palliative care cannot be achieved without access to pain relief and, when pain is severe, opioid analogesics in the class of morphine are recommended. The objective of this study was to examine the predictive relationship between a variety of country-level factors and opioid consumption in an estimated palliative care population in European countries.

Methods: This secondary data analysis comprised all 51 European countries reporting opioid consumption statistics to the International Narcotics Control Board in 2008. Each country’s total morphine equivalence (Total ME) opioid consumption per death from cancer and AIDS was the outcome variable, and was expressed as mg/death from cancer and AIDS. Total ME represents the aggregate amounts of five opioids indicated for the treating severe pain: Fentanyl, hydromorphone, morphine, oxycodone and pethidine. Three predictor variables were selected due to their bivariate significance with a country’s opioid consumption: Palliative care development, income level and government health expenditures. Descriptive analyses showed the statistical characteristics of the three predictor variables, and a multivariate linear regression model was constructed to determine their overall influence on the continuous dependent variable. An adjusted R² value estimated the goodness-of-fit accounted for by all variables included in the model.

Results: Only 39% of countries reported fully integrated palliative care and government expenditures on health ranged from 4% to 30%. The model was highly explanatory (adjusted R² = 78%), and all 3 predictors were statistically significant. Income level demonstrated the largest relationship, controlling for all other factors (p< 0.0001).

Conclusion: Although high income level was a strong determinant of a country’s opioid consumption, examples will be provided of low- and middle-income countries that are making progress to improve opioid availability.

Acknowledgment: LIVESTRONG and OSF

Abstract number: P236
Abstract type: Poster
Observational Study of Methadone for Cancer Pain, in PCU
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In France, methadone is only authorized for substitution, and oral way is the only available. In our palliative care unit (PCU) we can use it for the intractable pain, or opioid rotation, if we do the titration during a 48h-hospitalisation.

Aim: Describe level of pain relief, side effects after switching to methadone using a conversion ratio of 1/5 to 1/20 according to the baseline oral morphine equivalent dose (OMED) (100-1000 mg)

Methods: All the patients with methadone during 2006 where included, and pain assessment were undertaken with visual analogic scale (VAS), brief Pain inventory (BPI) and pain relief was expressed in percentage at day 0 (To), day 3 (T3), day 7 (T7), day 14 (T14).

Results: 15 patients (8 females) had methadone, aged 54 years (40-75), the cancer localisation was rectum (6), head and neck (4) and others (5). All patients experienced a mix of nociceptive and neuropathic pain. OMED prior switching is 578 mg (0-2000 mg), and at least 2 opioid rotations had already been done. All patients received coanalgesic treatment for neuropathic pain (anticonvulsants and tricyclics).

Between T0 and T3 the VAS score decrease from 2,59 points (0-5), between T0-T7 score decrease from 3,27 points (0-7)), between T0-T14 score decrease from 4,5 points (2-5)

The pain relief was important for 9 patients, mild for 4, none for one. The BPI score was improved for walk, sleep and well being. Methadone was stop because oral way was not possible anymore (5), or because of inefficacity (1).

Conclusion: Rotation for the methadone using a conversion ratio of 1/5 to 1/20 was safe and efficient. The pain relief was better at T14, probably due to the slow process of titration in this frail population.
Abstract number: P237
Abstract type: Poster

Breakthrough Pain in Cancer Patients Admitted to a Palliative Care Unit: A Prospective Pilot Study

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Background: Breakthrough pain (BtCP) is a complex heterogeneous pain, often difficult to manage. The aim of this survey was to characterise BtCP and assess the efficacy of their BtCP medication.

Methods: Patients admitted between September 2008 and August 2009 with stable background pain and experiencing one to four BtCP episodes daily were surveyed. BtCP characteristics, associated symptoms and impact were assessed using BPI speed of onset of BtCP medication was assessed using a stopwatch.

Results: 230 patients were assessed, 139 had BtCP of whom 30 met the inclusion criteria. 20 were female, the mean age was 59 years and performance status ranged between 2 and 3. Background pain was managed with a daily average oral morphine equivalent of 220mg. BtCP was treated with immediate release morphine (11 patients), IV morphine (4) and oral transmucosal fentanyl (15). The most common BtCP subtype was spontaneous nociceptive pain identified in 23 patients with an average peak pain intensity of 8 measured on a VAS. Almost all patients described a negative impact on their daily function. Seventeen patients were able to use a stopwatch to assess the speed of onset of their rescue medication. The average delay in receiving BtCP medication and to mean time to relief were 5.42 and 36.5 minutes respectively; no difference was seen between BtCP medication and to mean time to relief were 5.42 and 3.65 minutes respectively; no difference was seen between BtCP treatments.

Conclusion: BtCP had a significant impact on all patients surveyed. There was no difference in speed of analgesic onset between BtCP treatments although only approximately half of patients were able to use the stopwatch.

Abstract number: P238
Abstract type: Poster

Opioid Switching from Pure Agonists to TD Buprenorphine in Cancer Patients

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Aim: The aim of this study was to assess if patients who needs high doses of pure opioid agonists to obtain adequate pain relief can obtain the same degree of pain relief after switching to TD buprenorphine.

Methods: The trial was a prospective, multicentre and open-label study in patients with cancer pain. Patients included had satisfactorily controlled pain ( < 4 on NRS) with a stable daily dose of > 150 mg morphine or equivalent strong opioids (MED). Patients with MED < 240 mg/day started with 52.5 mkgr/h patches and patients with MED over 240 mg/day started with 70 mkgr/h. The patients continued with the same rescue opioid medication after switching. The patients were assessed at day 0,12,19 and 26 days regarding pain intensity, side effects, BPI and EORTC-QLQ. The patients also filled out a diary regarding sleep, average pain intensity, rescue medications, anti-emetics and laxatives.

Results: 18 patients were included. The MED/day before starting with buprenorphine patches were 150 - 516 mg with median 292 mg MED/day. The ending TD buprenorphine dose varied between 52.5 and 140 mkgr/hour with a median dose of 105 mkgr/hour. There were 5 drop-outs, the reason for the drop-outs were pain (n=3) and other reasons unrelated to the switching (n=2). The incidence and severity of side effects were comparable for the two treatments. The results between day 0 and day 26 from the BPI and EORTC-QLQ showed that the pain scores did not differ significantly however Global health status of the patients improved significantly over the 26 days. The patients diaries and the use of rescue medication has not yet been analysed.

Conclusions: Switching from high doses of pure opioid agonists to TD buprenorphine did not demonstrate any changes in pain scores and side effect profile.

The patients perceived statistically significant improvement in global health status after switching. A major weakness of our study is the low number of participating patients.

Abstract number: P239
Abstract type: Poster

The Efficacy of Lidocaine for Cancer Pain with Severe Abdominal Distention

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Abstract number: P240
Abstract type: Poster

An Audit of the Management of Breakthrough Cancer Pain

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Background: Breakthrough cancer pain (BTcP) has a prevalence of approximately 66%.1 Although there has been research surrounding management, there are no set guidelines. The Association for Palliative Medicine of Great Britain and Ireland (APM) devised 12 recommendations on optimal management of BTcP but these are based on limited evidence.2

Aim: To assess the management of BTcP in a tertiary oncology centre.

Objectives: The objectives focus on comparing current practice with standards developed with reference to the APM guidelines.

Method: This audit was a retrospective case note review.

Results: 56% of patients were experiencing pain; of these 43% had an assessment for BTcP. If the Palliative Care Support (PCST) or Pain Team (PT) were involved in patient care, 93% of patients had an assessment for BTcP. 52% of assessed patients were experiencing breakthrough cancer pain. Compliance percentages: consideration of treatment of the underlying cause (85%), consideration of avoidance of trigger (95%), reviewing of the background analgesia (95%), consideration of non-pharmacological (51%), consideration of non-opioids (97%), consideration of interventional technique (21%), reassessment of management (100%). Generally, these percentages were increased with PCST or PT input.

Conclusion: BTcP is a significant issue with few patients being assessed for this. Management for many patients is not ideal. However, PCST and PT involvement improve patient outcomes regarding pain. The results advocate the need to increase education throughout the trust.

References:

Abstract number: P241
Abstract type: Poster

Gabapentin Induced Acute Renal Failure in an 8-year-Old Boy - A Case Report

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Introduction: It is well established that dose adjustment is required for patients with renal impairment taking Gabapentin to prevent toxicity. To date, however there have been no reports of Gabapentin as a cause of renal failure.

Case report: The case describes an 8-year-old boy with recurrent rhabdomyosarcoma. He underwent surgical resection of his recurrent disease requiring left nephrectomy. His serum creatinine remained stable for a week postoperatively. He was then commenced on Gabapentin for postoperative neuropathic type pain and this was titrated upwards. His renal indices were found to have risen four days after commencing Gabapentin to 353 umol/L at which time it was discontinued. His renal indices rose to a maximum creatinine of 534 umol/L the following day and he became anuric.
On ultrasonography the right kidney was found to have increased in size when compared with a recent scan. Renal vascular investigations were normal. The surgical team confirmed that the right kidney was neither grossly diseased nor affected intra-operatively.

The working diagnosis, given the timing of Gabapentin administration was Gabapentin induced acute renal failure. The patient commenced venous dialysis and IV methylprednisolone with rapid resolution of renal indices to normal levels.

**Conclusion:** We suggest that Gabapentin be used with caution in patients with renal impairment and that Gabapentin be considered as a reversible cause of acute renal failure should the temporal relationship exist.

**Abstract number:** P242

**Abstract type:** Poster

Pain in Palliative Care in Portugal

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**Objective:** To study the prevalence, intensity and drugs used for the treatment of pain in palliative care in Portugal.

**Methods:** A cross-sectional survey in 10 of the 21 palliative care teams invited which accept to participate was carried out. Data of all patients observed on the 18th week of 2011 were collected. The data concerns only the day of the assessment.

**Results:** 164 patients were included in this study. 151 (92%) had cancer. Pain was directly assessed in 137 (84%) of the patients, whereas 27 patients could not report pain because of cognitive failure. The intensity of pain was rated using a 5 point verbal rating scale from none to maximum. Of those directly assessed 77 (56%) had pain at that moment; 42 (55%) mild; 25 (32%) moderate; 9 (12%) severe; 1 (1%) maximum. Non-opioid analgesics were used: paracetamol in 61 (37%) patients and NSAID in 20 (12%). Tramadol was the opioid for mild to moderate pain used: 21 (13%) patients oral (O), and 4 (2%) subcutaneous (SC) or intravenous (IV). Opioids for moderate to intense pain were: morphine O 38 (23%), SC 30 (18%), 3 (2%) IV; Transdermal (TD) fentanyl 32 (20%); buprenorphine TD 28 (17%); other 7 (4%), such as methadone O, alfentanil SC, hydromorphone O and buprenorphine sublingual. The adjuvants more often used were: corticosteroids 38 (23%), mainly dexamethasone; gabapentin 37 (23%); amitriptyline 15 (9%); pregabalin 6 (4%); and sodium valproate (3%). Rarely ketamine, baclofen, and pamidronate were used. The median dose of morphine was: O - 40 mg (10-360); SC - 45.2 mg (10-160). Opioids were used by the epidural route in 3 patients. No other invasive techniques were used for pain control.

**Conclusion:** The prevalence of pain is similar to the one reported in other studies: However, severe pain is somewhat lower probably reflecting the different settings where the study was carried out.

**Abstract number:** P243

**Abstract type:** Poster

Do Corticosteroids Have Immediate Analgesic Effects in Palliative Cancer Patients with Pain? A Randomized, Placebo Controlled Trial

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**Background:** Corticosteroids (CS) are recommended as alternative co-analgesics together with opioids. The evidence for CS as analgesic in cancer pain was evaluated in a systematic literature review recently performed by our research group. Five RCTs were identified, but only one could be used for efficacy analysis, concluding that CS may have a moderate analgesic effect in cancer patients. Evidence level was graded “very low”.

Based on this finding, a randomized study was initiated to investigate if corticosteroids do have an analgesic effect in cancer patients.

**Methods:** This multicentre trial was initiated with five participating centres in Norway. Patients were recruited at palliative care and cancer clinics.

Participants were adult cancer patients receiving opioids with pain score ≥ 4 measured by numeric rating scale 0-10 (average pain intensity last 24 hours) (aPI) and with...
expected survival more than four weeks. Exclusion criteria were: excruciating pain, opioid dose adjustment last 48 hours, diabetes mellitus, peptic ulcer disease, manifest spinal cord compression, severe cognitive impairment, or either prescribed steroids or started antitumour treatment the last 4 weeks.

Patients received methylprednisolone 16 mg twice daily or placebo over a period of 7 days. Short acting opioids could be used as needed.

Primary outcome was aPI at day 7. Secondary outcomes were fatigue, appetite, sleep quality, and analgesic consumption.

Results: Inclusion started May 2008; estimated sample size was 55 patients. By October 2011; 49 patients are included. We plan to reach the required number of patients by December 2011.

In the preliminary statistical analysis, pain (aPI) will be reported as mean values with 95% CI, and the groups will be compared using Student’s t-test with a significance level of 0.05.

Conclusion: Final results from the study will be presented. Sykehuset Telemark HF funded the study

Abstract number: P244
Abstract type: Poster

Initial Experience with Palliative Care Needs of Terminal Cancer Patients in a Northern City of Turkey

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Introduction: Palliative care (PC) research results obtained from one country can’t be applied directly to another without considering the needs, validity, and supply of that country. Here we would like to present our initial experience with the presentation, symptoms, and needs of terminal cancer patients in a Northern city of Turkey.

Patients and methods: The study was conducted in Department of Anesthesiology, Gaziosmanpaşa University between April and November 2011. The demographic data, medical and social history, primary tumor and treatment history, the symptoms, Karnofsky performance and Edmonton palliative score were evaluated and recorded.

Results: Thirty-three patients (20 male, 13 female) were included. The mean age of patients were 61 y (36-85 y). The mean BMI of patients was 22.8±18. The patients (n:31) were referred from mainly surgical clinics (94%). The primary tumor was of gastrointestinal origin in 11 patients (33%), and the rest was scattered among genitourinary (24%, n:8), lung (12%, n:4), endocrine and hematological malignancies. Eighty-eight percent of patients (n:29) had metastasis, mainly peritoneal (31%, n:9), lung (24%, n:7) and liver (14%, n:4) metastasis. The level of income was low in 70% of patients. Most patients were from urban settlement (70%). Thirty-two (97%) patients lived with their nucleus families. The main symptom of the patients were pain (79%, n:26). Other symptoms were, fatique (6%, n:2), dyspnea (6%, n:2), nausea(3%, n:1), itching (3%, n:1), constipation (3%, n:1). The mean Karnofsky performance scale was 53%. The mean Edmonton palliative score was 12±7. The mean palliative performance scale was 49%. Twenty patients were satisfied with the care provided by health professionals and families (61%).

Conclusion: Effective pain management is an essential part of PC since most patients suffered form intractable pain. The appropriate organization of pain units to provide PC is necessary during the institution of PC in Turkey.

Abstract number: P245
Abstract type: Poster

Assessment and Management of Adult Cancer Pain: Lessons from a Systematic Review and Synthesis of Qualitative Studies

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Background and aims: Pain is a common and burdensome problem for people with cancer and their families. Despite evidence-based guidelines, assessment and management continues to be suboptimal due to barriers at patient, provider and system levels.

Our aim was to identify barriers and facilitators to cancer pain management from the qualitative literature and from these generate recommendations for improving cancer pain assessment and management within a comprehensive framework of patient care.

Methods: We conducted a systematic review and synthesis of peer-reviewed qualitative studies published since 2000. Electronic databases were searched in May 2011 for studies exploring relevant perceptions of patients, caregivers and/ or health professionals. Article quality was rated using Kitto et al’s (2008) checklist. ‘Results’ sections were thematically synthesized using Thomas and Harden’s (2008) 3-stage process.

Results: Of 658 articles screened, 69 met criteria, reporting perspectives from 48 patient, 18 caregiver and 20 health
professional samples. Cancer pain and associated needs were identified by patients and caregivers as personal and multidimensional. Communication and education were highlighted as aspects of service delivery in particular need of improvement. A model of patient-centred care by Mead and Bower (2000) was a good ‘fit’ for descriptive themes across articles. Authors rarely reported on reflexivity or negative cases.

**Conclusion:** Our findings add to existing data by highlighting the need to embed patient and caregiver education within routine communication and patient-centred assessment and management. This should empower patients and families to better manage pain. Health professional education should focus on communication skills required for pain assessment and management.

Funding New South Wales Cancer Institute

**Abstract number:** P246  
**Abstract type:** Poster

**Pharmacokinetics of Fentanyl; Focus on Immediate Release Medication**

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**Introduction:** Fentanyl is a widely used opioid in cancer pain. It is more potent than morphine, highly lipophilic and binds strongly to plasma proteins. Several administration routes have been developed in the last years. We performed a systematic review on the differences in pharmacokinetics of the different administration routes of fentanyl. In this abstract we focus on immediate release fentanyl products. Besides that, we wanted to know if healthy people and cancer patients differ with respect to the pharmacokinetics.

**Methods:** Electronic searching in PubMed and Embase was performed using the terms fentanyl (including all separate administration routes), pharmacokinetics, metabolism, excretion and distribution.

**Results:** 80/957 identified studies appeared to fit the aim of the review; 42 on the immediate release products. Six different methods of administration were found: intravenous (IV, 8 studies), subcutaneous (SC, 2 studies), nasal (IFNS, 8 studies), buccal (FBT, 16 studies), sublingual (SL, 2 studies), transmucosal (OTFS, 10 studies). IV administration is used as the golden standard. Maximum concentration (Tmax) is at end of the infusion time. Bioavailability is near 100%. Tmax of SC and IFNS routes was 15 min; bioavailability was around 90%. FBC and SL routes have a Tmax around 40 min with a range of 20-240min. Tmax of OFTC is around 90 min with a similar range. Bioavailability is 50-70% for these last products. Almost all studies were done in healthy volunteers.

**Conclusion:** Tmax differs widely for the different fentanyl administration. Tmax of SC and IFNS routes are the closest to the golden standard. For the treatment of breakthrough pain in clinical practice, differences between the administration routes have to be taken into account. As cancer patients differ from healthy people, e.g. in organ function and comedication, studies on pharmacokinetics in cancer are needed. Furthermore, factors related to the large interpersonal variability have to be studied.

**Abstract number:** P247  
**Abstract type:** Poster

**Heart Rate Variability during Treatment of Breakthrough Cancer Pain with Opioids**

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**Aim:** It is well known that pain causes a dysregulation of the sympathovagal system. We hypothesized that the degree of this dysregulation could act as a surrogate marker for the intensity of pain in selected clinical situations. To investigate this hypothesis we monitored changes in the psychovagal system during treatment of breakthrough cancer pain (BTCP) by measurements of heart rate variability (HRV) and correlated these results with pain levels reported by patients.

**Methods:** We continuously measured HRV in palliative care patients with cancer who were treated for breakthrough pain with short acting (SAO) or rapid acting oral opioids (RAO). Simultaneously, the following measures of heart rate variability were recorded: total power, log low frequency (LF)/high frequency (HF), pNN50 and heart rate. Pain was estimated by patients using a numeric rating scale (NRS).

**Results:** So far readings were obtained from 4 patients with advanced cancer. Total power was low in all patients when BTCP occurred (mean: 2.800 ±/−2.200; range: 550-16.000) while NRS was high (mean: 6.5; range: 4.0-8.0). Mean total power measured within sixty minutes after initiation of oral opioid therapy showed an increase in all patients which resulted in an approximately 4 fold increase from baseline for the whole group (mean: 10.200 ±/−3000; range: 4.100 - 22.000; p= 0.23). Such trends were not observed in measurements of Log LF/ HF (44±13 vs. 46 ±26), pNN50 (42 ± 37 vs 62 ±82) or heart rate (90±37 vs. 124±32). NRS decreased to 4.5 (range 2-6).

**Conclusion:** Improvement of pain as reported by patients on a NRS were associated with an improvement of the sympathovagal balance as demonstrated by an approximately fourfold increase in total power. These preliminary results support the primary hypothesis of our study which is still ongoing.
**Abstract number:** P248  
**Abstract type:** Poster  

**Pain management in Outpatient Care Units in Germany - Empirical Results**  

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Nearly all cancer patients suffer from pain during the progression of the disease. Most of these patients prefer to stay in familiar surroundings until a crucial need for additional support has been reached. For employed outpatient care units the management of pain often becomes a major focus. Previous studies in other settings have demonstrated that pain can be significantly reduced when a systematic pain assessment is performed. Yet, little is known about how pain management in outpatient care units is carried out and what impact the German nursing guideline relating to pain management has on the clinical practice.

This study is part of a health services research project, which aims to analyze the degree to which the German nursing guideline on pain management is implemented in one particular city in Germany. Therefore all outpatient care units were invited to participate. A questionnaire based on the guideline’s focus was constructed and pretested. From June to August 2010 nurses (n=266) from 15 out of 42 outpatient care units were asked to partake in an online survey.

45.9% (n=122) of the invited nurses answered the questionnaire. Analysis shows that 92.6% (n=113) of nurses use a self-report pain assessment tool, mostly the numeric rating scale 81.3% (n= 89). Only 44.3% (n=37) of nurses use a proxy assessment, mainly the Doloplus (n=23). 59.2% (n=71) reported not having any written procedural instructions for the prevention of pain during painful procedures. 93.9% document pharmacological side effects. The majority (70.3%, n=85) lacks a systematic non-pharmacological treatment approach. Nevertheless 69.7% (n=) teach patients and family caregivers in using non-pharmacological approaches.

The results show a diverse picture of pain management for patients with cancer and their family caregivers in outpatient care units. They also identify specific needs for optimization towards a comprehensive pain management in outpatient care units in Germany.

**Abstract number:** P249  
**Abstract type:** Poster  

**Radiation Induced Pain in Head & Neck Cancer Patients Treated with Transdermal Buprenorphine Maintenance Therapy**  

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**Introduction:** Many head and neck cancer (HNC) patients suffer from radiation induced painful dermatitis and mucositis. The intake of oral analgesics is difficult or impossible due to radionecrosis related dysphagia. Therefore the use and efficacy of transdermal buprenorphine (TDB) for treatment of radiotherapy-induced pain in HNC patients is analysed.

**Materials and methods:** This prospective non-interventional study registered 46 consecutive HNC patients, that signed informed consent, and were treated by radiotherapy (RT) ≥50Gy-72GY in 5-8 w. ± chemo- or targeted therapy. Pain (measured with a visual analogue scale (VAS) 0-10) was initially treated with paracetamol (max. 4x1000mg/d) or tramadol(max. 400mg/d.). For insufficient pain relief, TDB was started at 17,5 µg/h and was gradually increased with 17.5 µg/h every 3 days untill the pain score was < 4 /10. Tramadol or buprenorphine sublingual were prescribed for breakthrough pain in doses equivalent to 1/6 or 1/12 of the daily TDB dose for resp. VAS-scores > of < 5/10. Weekly visits with the treating physician were appointed until the pain score was ≤4/10.

**Results and conclusion:** Moderate-severe pain (VAS>3/10) was present 3 w. after the RT-start and persisted min. 3 w. after the end of RT. Fifty percent of the RT patients needed TDB due to insufficient pain relief with oral analgesics. Patients treated with RT + CT or with RT >70Gy needed higher doses of TDB than those treated with RT < 70Gy. Laxatives were used frequently by patients receiving TDB.

**Conclusions:**  
1-Pain >3/10 is present from 3 w. after starting high dose RT or multimodality therapy and persists at least 3 w. after the end of RT.  
2-Half the HNC RT-patients need TDB because of insufficient pain relief with oral analgesics; Patients treated with RT + CT or with RT >70Gy needed higher doses of TDB than those treated with RT < 70Gy. Laxatives were used frequently by patients receiving TDB.

**Abstract number:** P250  
**Abstract type:** Poster  

**Assessment of Personalized Pain Goal (PPG) in Cancer Patients Referred to the Supportive Care Clinic for Pain Management**  

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**Aims:** Cancer pain quality improvement initiatives recommend tailoring pain treatments to patient’s (pt’s) individual goals. The pt’s PPG for pain relief (0-10 pain-intensity that pt considers to be comfortable in physical, functional, & psychosocial domains), is a simple measure of such goals. Study was conducted to determine feasibility & stability of PPG assessment, & to compare PPG-response to traditional pain response criteria.

**Methods:** Records of consecutive cancer pts seen in the Supportive-Care Clinic in consultation, & with follow-up visits within 1-6 weeks (n=465) were reviewed. Pain-responses assessed: clinical-response (CR; ≥30% or ≥2 point pain reduction), & PPG-response (pain ≤ PPG).

**Results:** 152 (34%), 95 (21%), & 163 (37%) pts presented with mild (1-4), moderate (5-6), & severe (7-10) pain, respectively. Median age (59 years), males (52%), advanced cancer status (84%) did not differ by pain category. Median PPG at initial consult was 3 (interquartile range, IQR 2-3), & similar across pain groups. Baseline PPG value was a 0, 1, 2, or ≥ 4 in 8 (2%), 23 (5%), 111 (25 %), & 66 (15%) pts, respectively. At follow-up (median 14 days), median PPG remained same (p=0.57) and PPG value was either the same or within +/-1 initial value in majority of pts (53 & 85% pts, respectively). CR was higher among patients with severe pain (60%) as compared to moderate (40%) & mild pain (33%, p<0.001). PPG-response was higher among patients with mild pain (63%) as compared to moderate (44%) & severe pain (27%, p< 0.001). Using PPG-response as gold standard for pain relief, sensitivity of CR was highest (98%) in pts with severe pain, but had low specificity (54%). In pts with mild pain, CR was most specific for pain relief (98%), but had low sensitivity (52%).

**Conclusion:** PPG is a simple patient reported outcome for pain goals. Majority of pts were capable of stating their desired level for pain-relief. The median PPG was 3, & it was highly stable at follow-up assessment.

**Abstract number:** P251  
**Abstract type:** Poster

**An Evaluating of Doloplus-2 in a Clinical Setting**

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**Aims:** Pain measurement in non-communicative older adults should be based on behavioral observation, e.g. using an observational measurement tool as Doloplus-2. The aims of this study were to examine the use of Doloplus-2 in a nursing home population without the ability to self-report their pain, evaluate its reliability and the criterion validity of Doloplus-2.

**Methods:** In this cross sectional study patients above 65 years of age that were unable to self report their pain were observed about their pain behavior using Doloplus-2. Doloplus-2, consisting of 10 items is divided into three subgroups: somatic, psychomotor, and psychosocial. The nurses also answered if they believed that the patients were experiencing pain (yes, no, don’t know) before they used Doloplus-2. Data on demographics, medical diagnoses, and prescribed pain treatment were collected from their records. Daily life functioning was measured and they were screened regarding their Mini Mental Status Examination.

**Results:** In total, 77 nursing home patients, 75% women with a mean age of 86 years (SD 6.6, range 68-100), were included. Over 50% was dependent on nursing care to a high or a medium extent, and all were severely cognitively impaired. Regarding Doloplus-2, the percentage of zero scores, indicating absence of the behavior, ranged from 17% (somatic reactions) to 40% (psychosocial reactions). Cronbach’s alpha was 0.71 for the total scale. In total, 52% of the patients were judged by the nurses to experience pain, compared with 68% when using Doloplus-2 (p= 0.01). Nurses were unable to report if the patients were in pain for 29% of the sample.

**Conclusion:** In the present study more patients were categorized to have pain using Doloplus-2 compared to nurses’ estimation of pain without using any tool and the nurses could not report if the patients were in pain in one third of the patients. These support the claim that Doloplus-2 is a useful supplement for estimating pain in this population.

**Abstract number:** P252  
**Abstract type:** Poster

**Drug Interactions in Palliative Care Patients with Intractable Cancer Pain and Polypharmacy: Focus on Hydromorphone**

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**Aims:** When multiple drugs are administered, the incidence of drug interactions and the risk of adverse drug reactions (ADRs) rise exponentially with the number of drugs used. The drugs most commonly involved are cardiovascular, psychotropics and anti-inflammatory agents. Many drugs may increase or decrease the activity of various CYP isozymes by either inducing the biosynthesis of an isozyme or by directly inhibiting the activity of the CYP. This is a major source of adverse drug interactions. We examined the safety of the use of hydromorphone (HM) in palliative care patients with intractable cancer pain and polypharmacy.

**Methods:** A retrospective analysis of 173 records of patients admitted to our palliative care unit between 01-2011 and 08-2011 was performed. Inclusion criteria: at least six different prescription drugs, intractable cancer pain, cancer pain management with hydromorphone during their hospital stay. Evaluation of symptom and disease-related data. Statistics: mean±SD, significance p < 0.05.

**Results:** 103 patients were included (age 70.0±14.0, 48 (46.6%) men). All patients had cancer in an advanced stage. Median Karnofsky index was 50 (range 20-80). In addition to inadequate control of pain in all patients, ADRs were responsible in 53 (51.4%) for hospital admission. Mean serum creatinine concentration was 3.0±1.0 mg/dl, and blood urea nitrogen 69.0±48.3 mg/dl. Opioids, antibiotics, antihypertensives and non-steroidal anti-inflammatory drugs were mainly responsible for gastrointestinal complaints and rash. Nausea, myoclonus and sedation were significantly reduced by use of HM. Analgesic response improved clearly. Mean daily dose of HM at discharge was 48.0±26.4 mg (360.0±198.0 mg morphine equivalence - considering an equianalgesic conversion ratio of M:HM = 7,5:1).

**Conclusions:** HM was well tolerated, safe and proved to be an efficacious and simple option for cancer pain treatment in patients with far advanced cancer with polypharmacy.

**Abstract number:** P254  
**Abstract type:** Poster

**A Characterization Study of Breakthrough Pain in Cancer Induced Bone Pain**

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**Purpose:** Cancer-induced bone pain (CIBP) is the commonest cause of pain in patients with cancer. CIBP exists as a combination of background and breakthrough pain (BTP). Whilst the characteristics of BTP in cancer have been described, less is known about BTP in CIBP. This study investigates the characteristics of BTP in CIBP.

**Patients and methods:** Patients in a multi-centre clinical trial assessing a novel treatment in combination with radiotherapy for CIBP were eligible. Data from trial baseline (analgesia, Brief Pain Inventory (BPI), Breakthrough Pain Questionnaire (BTPQ)) were assessed. Patient pain characteristics (BPI, BTPQ) were summarised using descriptive statistics. Analysis using Mann-Whitney tests was undertaken on patients who had ≤2 episodes of BTP per day versus >2 episodes.

**Results:** Data were available on 86 patients. The median (IQR) daily number of episodes of BTP was 4 (2-5) per 24 hours. The median worst pain severity was 7 (6-8) on a 0-10 Numerical Rating Scale. 71 (83%) patients had BTP of rapid onset (< 5min), 41 (47%) had BTP of short duration (< 15min) and 33 (38%) had BTP which was rapid onset and short duration. 31 (36%) patients were unable to predict BTP. 71 (81%) of patients were taking 81mg of mean morphine equivalent daily dose (MEDD) (95% CI 67-99; n=69). Patients who had >2 episodes of BTP had
greater mean total BPI score (51 vs. 36, p=0.0023), greater mean BPI Interference score (42 vs. 30, p=0.0084) and a greater mean MEDD (84mg vs. 57mg, p=0.2493) than those with ≤2 episodes of BTP.

Conclusion: In CIBP, breakthrough pain is often unpredictable, of sudden onset and short duration. Multiple episodes of BTP are associated with greater functional impairment and increased doses of opioids. Arguably in 36% of patients opioid analgesia is unlikely to be of benefit. Further work is required to improve the efficacy of breakthrough pain analgesia.

Abstract number: P255
Abstract type: Poster
Evaluation of Emergency of Admissions in Palliative Care Unit Patients Suffering with Pain - Causes and Challenges - Georgian Experience
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Aims: Usually patients are referred to the palliative care (PC) unit of National Cancer Centre (NCC) from: home based palliative care services, district outpatient clinics, GPs, Medical Oncologists and by emergency referral. Sometimes, patients suffering with pain are admitted for: opioids prescription or its adequate dose administration. The aim of the research is to identify the most frequent problems of patients suffering with pain and admitted in PC unit of NCC, outline the challenges and the ways of their further improvement. Study population: Were evaluated 716 patients admitted in PC Unit of NCC during the 2010-2011. In the study were involved 427 patients.

Methods: Presented study is prospective. Patients were evaluated by medical staff of PC Unit of NCC. Inclusion criteria were:

a) Cancer Patients with pain;

b) Age >18 years;

c) Life expectancy < 6 months;

d) Admitted for emergency reasons for pain and symptom control adequateness.

Exclusion criteria were:

a) patients in the dying phase of their illness evaluated by the admitting physician or nurse;

b) mentally ill patients.

The method of inferential statistics was used.

Results: Study showed that the main problem of emergency admission of those patients were increasing the pain score and from this number of patients in 99% of cases opioids administration were required. In 76% of cases opioids administration were first time and in 24% of cases increasing the dosage were needed.

Conclusion: Pain is still the most unresolved symptom for control (p< 0.001). The problems in pain management and related emergency admission at PC unit of NCC should be caused by lacking of:

1) legislative bases - limitation validation of prescription (7 days),

2) list and forms of opioids and their availability,

3) knowledge and experience of health care professionals - stigma and opioidphobia of society and health care professionals

The study was funded from Georgian National Association for Palliative Care.

Abstract number: P256
Abstract type: Poster
“Getting it on Time”- Administration of Breakthrough Cancer Pain Medication for In-patients at a Tertiary Cancer Centre
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Background & aims: Cancer patients may experience several episodes of breakthrough pain on a daily basis, requiring immediate-release strong opioid analgesics which are stored on each ward at The Christie NHS Foundation Trust in a centrally located controlled drugs cupboard. There could be significant delay in patients receiving these medicines whilst they are admitted to hospital due to various factors which are under-researched at present. We are presenting the preliminary results of a prospective audit conducted to determine whether patients’ are receiving strong opioid analgesics for breakthrough cancer pain in a timely manner at the largest cancer hospital in Europe.

Methods: 100 episodes of breakthrough cancer pain in medical oncology patients were observed over a 12 month period by ward based pharmacy staff, who timed the process of breakthrough pain administration, from the moment the patient asked a member of nursing staff for strong opioid analgesia, to them receiving it.

Results: Although the vast majority of breakthrough pain medication was administered in less than 10 minutes, there are processes that may be put into place in order to speed up the process of controlled drug administration, and increase patients’ access to breakthrough pain medication. The rate limiting step in the administration process was commonly the availability of a second member of trained staff to supervise the administration of the controlled drug, and the
availability of the controlled drugs cupboard keys, of which there may only be one set per ward.

**Conclusions:** The use of an Omnicell® machine, which removes the requirement of accessing the controlled drugs cupboard keys, by giving authorized staff a unique personal identification number reduced administration time and has the potential to facilitate appropriate access to controlled drugs, thereby improving patient experience and satisfaction.

**Abstract number:** P257  
**Abstract type:** Poster  
**Transcranial Brain Stimulation for Visceral Pain - A Pilot Project**  
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**Aims:** Visceral pain is difficult to treat in a palliative care situation. Opioids alone are often insufficient and there is a need for complementary methods to avoid side effects of high dose opioid treatment.

Therefore, we evaluated transcranial brain stimulation for the treatment of visceral pain syndromes. Previous research has shown that visceral pain increases excitation in the cortex area S II. Transcranial magnetic stimulation of this area reduced pain. However, there has only been a single case report of transcranial brain stimulation for the relief of visceral pain.

**Methods:** We started a placebo-controlled, double-blind, randomised crossover study. We used cathodal stimulation of the sensorimotor cortex in patients with malignat tumors and visceral pain syndromes. In a first phase, patients received during 5 days either verum or placebo stimulation. In the second phase, we provided verum stimulation for each patient. We collected demographic data and evaluated the pain and concommitant medication before and after each stimulation.

**Results:** Within 6 months we have evaluated 20 patients with visceral pain syndromes. Only 4 of them have been able to be included in the trial. The other patients have been in rapid progression after evaluation. Because of the low number a statistical evaluation of the data has not been done. Verum stimulation showed a positive effect even on long term pain in two patients. However, placebo stimulation reduced pain in two individuals. The only side effects have been sensory disturbances and tiredness during stimulation.

**Conclusions:** The use of transcranial brain stimulation for the treatment of visceral pain syndromes is a method which can be used for patients with advanced cancer. The method has only minor side effects and is safe and easy to use. However, a larger trial is needed to evaluate its effect on visceral pain control.

**Abstract number:** P258  
**Abstract type:** Poster  
**Anesthetic Procedures for Cancer Pain in a Palliative Care Unit**  
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**Aim:** The main objective of the study was to value the frequency of anesthetic procedures implemented at the Palliative Care Unit (PCU), and the efficacy of these techniques.

**Methods:** Descriptive study. We included, from January 2009 to April 2011, advanced oncologic patients with difficult-to-manage pain (pain could not be controlled despite the adequate pharmacologic treatment implemented, due to inefficacity or to intolerable secondary effects) followed by the PCU. The following aspects were valued: pain intensity, final quantity of opioids administered per day, measured in morphine equivalent mg/day, pain location, number of pain types, functional situation, further complications and survival ratio after technical realization.

**Results:** During the period described, a total of 982 patients were treated by our PCU. 75 techniques were practiced in 35 patients, 3.5% (1.9% in 2009, 4.1% in 2010, and 6.5% in 2011). 21 patients (60%) required more than just one technic. Out of this group of 35, 18 were male patients. Average age was 57 years (23-84). Overall, 55 Ganglion, Plexus or Sympathetic Blocks and 20 Epidural Catheters were practised. Average pain intensity at the beginning was of 8.7 (range 5-10) and right after the technique was applied 2.7 (range 0-5). Morphine consumption dropped from 250 to 210 (bigger drop in those patients with Plexus Blocks and smaller in those with Epidural Catheter). The median survival has been of 47 days (6-800). (Epidural Catheter 39.2 days vs Plexus Blocks 79.4 days). 8 patients' developed 10 complications (11%). Most of these complications appeared in patients with epidural catheter. All complications were sorted out and solved with no further problems nor serious sequels.

**Conclusions:** We have practiced an increasing number of invasive anaesthetics procedures in palliative care patients with good results and few complications. Larger experience is needed to implement better the different techniques used.

**Abstract number:** P259  
**Abstract type:** Poster  
**Otofen: A New Drug for Break through Cancer Pain**  
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This experimental study, made in collaboration with Naples, Venice, Pisa, Arezzo and Grosseto pain centers, shows how fentanyl through the ear may give a good pain relief in patients affected by cancer pain either in base therapy or in break through cancer pain.

60 patients have been enrolled in this study. Among those patients nearly 50% at T0 showed a VAS of 8; at T1(after one week) their VAS was 2.

**Conclusions:** This new drug is extremely effective in the treatment of cancer pain at a very cheap price.

**Abstract number:** P260
**Abstract type:** Poster

**Comparison of Disease Progression and Clinical Characteristics of Black Caribbean and white British People Living with Severe Multiple Sclerosis in the UK**

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**Background:** Multiple sclerosis (MS) prevalence is now similar among some black and minority ethnic (BME) groups compared to white British people. It is thought that ethnicity may influence the clinical impact of MS but no studies have explored MS progression and symptom impact across different ethnic groups.

**Aim:** To examine the MS disease profile and characteristics of black Caribbean (BC) and white British (WB) people with an EDSS of ≥6.0 (severe disease).

**Design:** Comparative cross-sectional survey using established measures of disability and symptom burden. The Progression Index (PI) was used to examine progress of MS from illness onset. Data were analysed using parametric (t-test) and non-parametric tests (Mann-Whitney U).

**Setting:** 2 NHS hospital trusts and 6 primary care trusts covering 6 London boroughs.

**Results:** 53 BC and 110 WB people with MS (PwMS) were identified. 42 BC (79%) and 43 (40%) WB PwMS agreed to participate. There were no differences in gender or the distribution of EDSS. Age when first symptoms were experienced was similar for both groups (M 34.3 and 34.1 yrs). However, BC PwMS were younger at diagnosis (M 37.4 yrs) than WB PwMS (M 41.4 yrs), and had been living with MS for a shorter time period before reaching the same disability (M 10.3 v/s M 16.1 yrs). They also had a higher mean PI (M 0.4) than WB PwMS (M 0.3) (p=0.02). Both groups reported high symptom burden from their MS that included significant depression and anxiety. BC PwMS were identified as being more cognitively impaired than WB PwMS (M 5.9 v/s M 3.4, p=0.004) where as fatigue was a slightly greater issue among WB than BC group (M 22.3 v/s M19.3, p=0.058).

**Conclusions:** We identified BC PwMS experience higher rate of disease progression and are at higher levels of cognitive impairment than WB PwMS. This highlights the need for timely identification and management of this potentially vulnerable group of patients by neurology and palliative care services. Funded by MS Society.

**Abstract number:** P261
**Abstract type:** Poster

**Subcutaneous Lymphoedema Drainage - An Irish Experience**

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**Aim:** Secondary lymphoedema is caused by the expansion or removal of lymph nodes due to malignancy, surgery, radiotherapy and infection. Lymphoedema is experienced by up to 42% of breast cancer patients following a lymph node dissection and up to 75% will be due to malignancy. Up until now the mainstay of treatment has been pharmacological therapies such as diuretics and mechanical therapy with compression and manual lymphatic drainage (MLD). Subcutaneous lymphoedema drainage is a novel technique involving the insertion of 19G butterfly needles under the skin to remove the lymph/subcutaneous fluid and reduce the size and discomfort of lymphoedemic limbs. It is used in refractory lymphoedema. Upon presenting a Grand Round to the Mid-Western Regional Hospital, Limerick on the procedure we discovered that the technique was virtually unknown. We have had some good results at our institution and are interested in the views and experiences of other palliative medicine physicians.

**Method:** We conducted an 8-point survey to send to all specialist palliative care centres. Questions include; numbers of patients presenting to the service with lymphoedema, limbs affected, treatments trialled and the successes, whether they were familiar with the technique, what the experience has been and concerns regarding subcutaneous lymphoedema drainage. Ethical approval has been requested.

**Results:** The data collected will allow us to gauge the need for such a technique and the experiences of other centres with this procedure. The results of this and our institution’s results will then be available for presentation.

**Conclusion:** Lymphoedema is a common and concerning condition in the palliative medicine community. Subcutaneous lymphoedema drainage is a relatively easy and well tolerated procedure that has significantly improved the pain and discomfort associated with this debilitating condition.
Abstract number: P262
Abstract type: Poster

Frequency of Depression among Oncology Outpatients and Association with Other Symptoms

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Purpose: Depression occurs among an estimated 15% of cancer patients (range, 1% to 77.5%). Our main objective was to identify the frequency of reported depression by using the Brief Edinburgh Depression Scale (BEDS) among cancer outpatients. Our secondary objective was to identify associated symptoms of cancer using the Edmonton Symptom Assessment System (ESAS), and to evaluate the screening performance of depression between ESAS and BEDS.

Methods: In this multicenter prospective study conducted, we used the ESAS to collect information on 9 symptoms: pain, fatigue, nausea, depression, anxiety, drowsiness, shortness of breath, lack of appetite, feeling of well-being (each rated from 0 to 10). The BEDS was used to assess for “probable depression” (score >6). Data were analyzed using parametric and non-parametric test.

Results: A total of 146 patients completed the study. The prevalence of probable depression was 43/146 (29%). Probable depression was associated with increased fatigue (p=0.008), depression (p< 0.001), anxiety (p< 0.001), shortness of breath (p= 0.01) and decreased feeling of well-being (p< 0.001). Among patients with probable depression, 42 (98%) patients were not using antidepressants. Regarding the sensitivity and the specificity, we determined that the optimal cutoff for using the ESAS as a depression screening tool was ≥2.

Conclusion: We found significant associations between probable depression as determined with the BEDS and 5 symptoms as detected with the ESAS. The vast majority of patients with probable depression were not receiving pharmacological treatment. Depression should be suspected in patients with higher symptom distress as for any one of these 5 ESAS items.

Abstract number: P264
Abstract type: Poster

Prescribing Preferences for Malignant Bowel Obstruction in Palliative Medicine

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Aims: Malignant bowel obstruction (MBO) can be a distressing and debilitating complication for palliative care patients. The choice of treatment for MBO is not standardised and is clinician dependent. The aim of this national survey was to examine the prescribing preferences of palliative medicine clinicians for the treatment of MBO.

Methods: A cross-sectional online survey was sent out to Australian palliative medicine clinicians. Participants were presented with a clinical vignette about a patient with metastatic ovarian cancer with extensive intra-abdominal disease with an acute MBO for medical management. Participants were asked about non-pharmacological measures, and the first medication of choice for treatment, dosing and review schedules, maximum doses, and possible side effects. Participants were asked to offer the same information about their second medication of choice.

Results: One hundred and five participants responded with 192 treatment choices. The majority would use a nasogastric tube on free drainage. Twelve medications were nominated. Haloperidol, followed by dexamethasone and hyoscine butylbromide, was the most common first line treatment, and octreotide and cyclizine the second line treatments. There were considerable variations in starting and maximal doses, however most would review patients by 24 hours.

Conclusion: There were large variations in the treatment of malignant bowel obstruction amongst palliative care clinicians. Even for a single medication, the dosing was inconsistent. This highlights the need for well-designed studies of malignant bowel obstruction treatment in palliative care patients to guide treatment choices and dosing.

Abstract number: P265
Abstract type: Poster

A Randomized Cross-over Clinical Trial to Evaluate the Efficacy of Oral Transmucosal Fentanyl Citrate in the Treatment of Dyspnea on Exertion in Patients with Advanced Cancer

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The aim of this phase II clinical trial is to determine the effectiveness of OTFC in the treatment of the effort dyspnea in patients with advanced cancer and provide the drug safety data in this population. It is considered that the treatment is effective if it achieves an improvement of symptoms of dyspnea after taking the 6-minute walk test (6MWT) in the least 50% of patients treated.
This is a crossover clinical trial in which the study population will do the 6MWT with the study drug and placebo. Selection criteria: patients must have dyspnea at rest or dyspnea moderate effort with an intensity of at least 3 on a scale from 0 to 10. (EUDRACT : 2010-021399-26).

**Primary variable:** VAS scale change from baseline. Improvement of the severity of dyspnea after completion of the 6MWT in patients with advanced cancer. Response to treatment was considered an improvement greater than or equal to two points on the previous level of dyspnea. The evaluation and determination of changes in the level of severity of dyspnea is done through Visual Analogue Scale (VAS) included in the Edmonton Symptom Assessment System (ESAS).

**Secondary variables:**
- The treatment impact in basal oxygen saturation.
- The distance covered in the 6MWT with and without medication.
- Edmonton Symptom Assessment System (ESAS) scale change from baseline.
- The apparition of the adverse event due to the treatment.

**Results:** At present 11 patients were enrolled. Preliminary results will be presented.

**Conclusion:** Preliminary results don’t support the initial hypothesis. Pending completion of the recruitment.

**Abstract number:** P266  
**Abstract type:** Poster  
**Security Hunger: An Understanding of Cancer Cachexia-related Distress in Families**

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**Aim:** Weight loss and anorexia are symptoms of cancer cachexia syndrome that can be experienced as distressing by patients and their family members. This study aimed to develop a theoretical understanding of cachexia-related distress that can underpin family-focused psychosocial interventions for the problem.

**Methods:** A novel understanding of cachexia-related distress was generated from a secondary analysis of 63 in-depth, semi-structured interviews conducted in the South of England in 2006-7 with 31 advanced cancer patient-family carer dyads (a total of 62 interviews). The two stages of analysis comprised a discourse analysis followed by thematic analysis and interpretation, which revealed interdependency in patient and family carer experience and enabled the construction of a conceptual model. Pre-existing theory was then used to explain the model and generate propositions of how cachexia-related distress might be alleviated. Emergent concepts, propositions and theory were tested through engagement with the study Expert User Involvement Group comprising healthcare professionals, academics and patients.

**Findings:** Our food habits are a taken-for granted behaviour that can communicate connection with and separation from those around us. Interactional patterns between patient and family carer are disrupted by weight loss and changing eating habits. Dyads can either adapt to this change (dual acceptance) or resist (dual resistance or mismatched resistance). Resistance can be understood as an indicator of threat to emotional security and driven by security hunger. Cachexia-related distress in both patients and their family members is symptomatic of unstable connections and difficulty adapting relationships as disease progresses.

**Conclusion:** This theory challenges researchers and clinicians to seek ways of aiding not only with the symptoms, but also with adaptation to the inevitable relationship disruption in families affected by cancer cachexia syndrome.

**Abstract number:** P267  
**Abstract type:** Poster  
**How Do I Inhabit a Disintegrating Body?**

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**Aims:** To understand the experience of disrupted embodiment for people with advanced cancer.

**Methods:** Ten patients with end stage cancer were interviewed in their homes. Participants had an Australian Karnofsky Performance Status Score between 50 to 70 and ages ranged from 51 years to 95 years. Perspectives were sought on their experiences of disrupted embodiment and functional decline and how these changes affected their day to day lives. Interviews were recorded, transcribed verbatim and analysed guided by Colaizzi’s methods. Transcripts were mapped against the conceptual frameworks of embodiment (Gadow, 1982, Leder, 1990) and occupation (Kielhofner, 2008).

**Results:** All participants experience relentless progressive bodily breakdown. They have no alternative but to live in bodies that are literally disintegrating in front of their eyes: crumbling, leaking, wearing down, turning into living skeletons. Bodies are experienced as unfamiliar, intrusive, and bewildering - confronting but inescapable. Emotional responses to these changes are unique to each individual and influenced by the meaning each person attaches to the experience. A lucid mind, cognisant of deterioration,
only serves to heighten the experience of vulnerability. Some experience their bodies as an object of disgust, perceiving them as abhorrent to others, particularly when bodies are unbounded. It is impossible to sever self from body and physical sensations associated with deterioration are experienced as an intrusion, both physically and emotionally.

**Conclusion:** In order to develop effective partnerships with the patients in our care, we need to better understand both the experience of bodily symptoms and how these impact everyday life. This study provides empirical support for and builds upon Gadow’s (1982) dialectic progression of relationship between body and self during ageing and illness. These insights have potential to inform clinician assessments and interventions.

**Abstract number:** P268
**Abstract type:** Poster

**Duration, Severity and Frequency of Episodic Breathlessness (EB) in Patients with Advanced Diseases**

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**Background:** Acute episodes of breathlessness (synonyms: acute, incident, breakthrough) are common in advanced disease and pose a major burden on patients but detailed information about the characteristics are lacking.

**Aim:** To describe the characteristics of episodic breathlessness (EB) in patients with breathlessness due to lung cancer (LC), chronic obstructive pulmonary disease (COPD), chronic heart failure (CHF), or motor neurone disease (MND).

**Methods:** Survey as part of a mixed methods study with seven questions on EB. Interviews took place in five outpatient clinics at two university hospitals in South London/UK. Descriptive analysis was conducted.

**Results:** 49 patients with breathlessness (14 CHF, 14 COPD, 13 LC, 8 MND) were included (mean age 68.3 years (SD 12.1), 59% (29/49) men). Participants had a median Karnofsky of 60 (range 30-90) and mean general breathlessness intensity (average over the last 24h) was 3.2 (SD 1.7) on NRS (0-10). All experienced EB but 78% (38/49) reported continuous breathlessness in addition. 24% (12/49) reported episodic breathlessness during night time. Some participants provided descriptions about more than one episode but not everyone described all characteristics. Most episodes (79%) were less than 10 min and only 6% (4/70) lasted 1-3 hours. 55% (33/60) had a quick onset (in contrast to gradual onset, defined by participant). Mean severity of 66 episodes was 7.0 (SD 1.6) on an NRS (0-10). 55% (11/20) experienced more than one episode per day but described that the frequency of EB depended on their activity (exertion as a trigger for EB).

**Conclusion:** Most episodes of breathlessness are short, occur daily and with high intensity. This has implications for the management as most short acting drugs have a longer onset of action than the actual duration of EB. Therefore, either drugs with very quick onset of action are necessary or patients need to be taught self-management strategies to control these episodes effectively.

**Abstract number:** P269
**Abstract type:** Poster

**The Pharmacological Effect of Psychostimulants in Advanced Cancer Patients through a Qualitative Study: Other Way to Find Relevant Research Outcomes with Clinical Trascendence**

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**Background:** There are increasing interest in the effect of psychostimulants (P) in relief asthenia. It is possible that the effect of these drugs go beyond the fatigue.

**Aim:** To address with qualitative approach the patients experience with methylphenidate (MP) or modafinil (MD).

**Method:** Advanced cancer patients, receiving MP or MD for symptom control. Patients and main caregiver were interviewed after to administrate the first doses of the drug (day 1-3) with open questions. Content analysis of field notes was carried out.

**Results:** 36 patients included (59 years, KPS 50-60%, 50% in last 6 weeks). Received MP 15, MD 21. Asthenia was main indication in 29. Main domains influenced: vitality (n=22) (“activity is unbelievable now”), asthenia (n=7) (“I feel less fatigue and more restful”), cognitive functions (n=16), and mood (n=22) (“yesterday I was the sadness (so sad), today I am other”). Improvement in general wellbeing was noted. Positive effect was found in all cases but one. Tolerance was excellent. Sub-themes identified in each area included mindfully details: the patient talk only some times about fatigue but yes about strength, tone or vitality. It is also worth to see how many times the patients related a change in the physical capacity of doing activities (stand alone, walking, going out, etc.). Our data show better cognition and less somnolence but also improvement in language or communications (picking up the phone, longer conversations, etc.). About mood is surprising how related
with a coming backs with the cheerfulness are the P: words as ‘happy’ or ‘happiness’ were using. Clear expressions, deep and lyric in some sense (‘I’m back’, ‘I am more me’) showed the better status. Effect ‘off-on’ is described.

**Conclusion:** P can play a therapeutic role in palliative care patients even at the very end of life. Qualitative analysis of their pharmacological effect found unexpected outcomes clinically relevant. Founding: University of Navarra.

**Abstract number:** P271

**Abstract type:** Poster

Opioid Toxicity: The Patient Experience

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**Aims:** Opioids are widely prescribed for the management of cancer pain and it is well recognised that some patients will experience side effects or toxicity. The study explores the patient experience of opioid toxicity as part of a longitudinal study that aims to characterise opioid induced hyperalgesia (OIH) and identify possible predictive factors of OIH.

**Methods:** Following ethical approval and written consent semi-structured interviews are carried out with patients who have previously been opioid toxic. The interviews are recorded and transcribed before being analysed using grounded theory. Emerging themes are presented.

**Results:** 12 interviews have been recorded and analysed with further interviews planned. The patients experienced symptoms of opioid toxicity for variable lengths of time ranging from hours to months before they were recognised and managed. The majority of patients did not realise the symptoms were due to the opioids and there was a general lack of awareness about the potential side effects of opioids. Patients described loss of control and gaps in memory associated with the opioid toxicity. Several patients also reported a sensitivity of the skin (which was found unexpected outcomes) at the site of their pain or a whole body pain at the same time as they were not usually associated with their pain) at the site of their pain even at the very end of life. Qualitative analysis of their pharmacological effect found unexpected outcomes clinically relevant. Founding: University of Navarra.

**Discussion:** Lack of patient awareness about potential side effects and features of opioid toxicity leaves patients vulnerable. Providing information when commencing an opioid would give patients and their informal carers some control and enable episodes of toxicity to be managed more quickly. In particular the whole body pain reported suggests OIH may be easily recognised if the right questions are asked.

**Abstract number:** P272

**Abstract type:** Poster

Aromatherapy as Symptom Relief for Cancer Patients

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**Purpose:** Cancer patients suffer various symptoms and influence on patients’ and their families’ quality of life. They are usually treated by medications but we sometimes experience difficulties in symptom management only by medication. We study the effect of aroma therapy for physical and psychological symptom of cancer patients.

**Method:** Cancer patients, consulted by palliative care team from May 2009 to September 2011, who received aromatherapy for symptom relief were recruited. The M. D. Anderson Symptom Inventory Japanese version (MDASI) were used just before and after aromatherapy. Statistical analysis was performed.

**Result:** Among 67 patients treated aromatherapy, 13 patients agreed to participate in this study. Male and female ratio is 1/12. Average age is 62.5 year old. Initial symptoms are fatigue 12 (92%), pain 6 (46%), edema 6 (46%), dyspea 3 (23%), others 3 (23%). Their medications are 10 by opioid, 9 by glucocorticoid. Frequency of aromatherapy is 4 (1-11), which are massage (legs, arms, back) or aromatic bath. Popular essential oil is lavender, agusteforia, sweet orange, rosewood. Fatigue, distress and enjoyment of life are significantly improved (P=0.002, 0.027, 0.043) after aromatherapy.

**Conclusion:** Patients and family in end of life have various pain and symptom. We should perform enough assessment and comprehensive palliative care. Aromatherapy is also useful and available for pain and symptom relief.

**Abstract number:** P273

**Abstract type:** Poster

Symptoms Other than Pain in Palliative Care in Portugal


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Objective: Descriptive study of the prevalence and the intensity of symptoms other than pain in the activity of Portuguese palliative care teams.

Methods: A cross-sectional survey in 10 of the 22 palliative care teams invited which accept to participate was carried out. Data of all patients observed on the 18th week of 2011 were collected. Data concern only the day of the assessment. The intensity of symptoms was rated using a 5 point verbal rating scale from none to maximum. In patients with cognitive failure the signs of discomfort observed were rated with the same scale.

Results: 164 patients were included in this study. 151 (92%) had cancer. Symptoms were directly assessed in 137 (84%) of the patients, whereas 27 patients could not report their symptoms due to cognitive failure. In the 27 patients with cognitive failure dishonesty was rated as mild in 15 (56%), moderate in 10 (37%) and severe in 2 (7%). The main symptoms prevalence in the patients who could be assessed directly was (the severe to maximum intensity percentage is calculated for the number of each symptom): fatigue 116 (85%), severe to maximum (SM) 43 (37%); depression/sadness 107 (65%); SM 34 (31%); anxiety 84 (51%), SM 21 (25%); anorexia 84 (51); SM 19 (23); somnolence 71 (52), SM 11 (16%); constipation 56 (41), SM 9 (17%); dyspnea 43 (31), SM 5 (12); insomnia 40 (29), SM 8 (21%); nausea 26 (19), SM 6 (23%). Other problems were: pressure sores - 31 (19%); neoplasic wounds - 25 (15); ascites - 23 (14%); pleural effusion - 18 (11); lymphedema - 13 (8).

Conclusion: Fatigue, psychological and anorexia were the predominant symptoms other than pain which is similar to the findings in other studies.

Abstract number: P274
Abstract type: Poster

Acceptability and Preferences of Six Different Modes of Drug Application for Acute Episodes of Breathlessness (EB) - A Comparison Study between Two Countries
Niemand A.1,2, Bausewein C.2,3, Voltz R.1, Higginson I.J.2, Simon S.P.1,2,3
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Background: Opioids are the drugs of choice for the treatment of breathlessness but acute episodic breathlessness (EB) remains difficult to manage. New modes of opioid applications with quicker onset of action seem to be very attractive for the management of EB but we don’t know how acceptable these are for patients suffering from EB.

Methods: This study aimed to determine the acceptability, previous experience and preference of different modes of drug applications of breathless patients suffering from life-limiting diseases (lung cancer (LC), chronic obstructive pulmonary disease (COPD), chronic heart failure (CHF), motor neurone disease (MND)). Participants were recruited in UK and Germany and asked in a face-to-face interview using images and explanation to illustrate six application forms (oral, inhaled, sublingual, intranasal, buccal, transmucosal (lollipop)).

Results: In total, 119 participants (UK n=48, Germany n=71) were included, 60% male, mean age 67.7 years (SD 9.9), half of the patient suffered from COPD (50%). Inhaled was the most accepted mode of application (87%), followed by sublingual (46%) and intranasal (42%). Oral was least accepted (24%) and preferred (9%) form during breathless episodes although nearly all participants had previous experiences with it (98%). Ratings were similar in both countries but different for preferences of sublingual (UK>Germany) and intranasal (Germany>UK). In general, participants from the UK rated more often ‘yes’ for acceptability compared to Germany.

Conclusion: Inhaled was the most accepted and preferred mode of application for episodic breathlessness in both countries and oral the least accepted form but no mode seemed to be acceptable to all patients. Therefore, individual patients’ preferences should be explored before drug prescription to enhance compliance and convenience.

Abstract number: P275
Abstract type: Poster

Contending with Deterioration: The Work of Adaptation at the End-of-Life
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Aims: To explore ways in which people adapt to functional decline at end-of-life.

Methods: Ten patients with end stage cancer were interviewed in their homes. Participants had an Australian Karnofsky Performance Status Score between 50 to 70 and ages ranged from 51 years to 95 years. Perspectives were sought on their experiences of disrupted embodiment and functional decline and how these changes affected their day to day lives. Interviews were recorded, transcribed verbatim and analysed guided by Colaizzi’s methods. Transcripts were mapped against the conceptual frameworks of
embodiment (Gadow, 1982, Leder, 1990) and occupation (Kielhofner, 2008). One page interview summaries were sent to participants for member checking.

**Results:** People value opportunity to be as independent as possible but increasingly need to rely on others. Bodies change rapidly with palliative illness and people need to constantly reframe expectations they have of themselves and their functional abilities. When bodies don’t respond in familiar ways but desire to participate in daily life remains, strategies are employed to manage these changes. Participants had to forward plan movements and work differently with their bodies to engage in activities. Receiving assistance from others was inevitable but met with deep ambivalence. Clinicians play an important role in either aiding or hindering adaptation to functional decline.

**Conclusion:** Although functional decline at the end-of-life is relentless, the work of adaptation matches this. It is through the testing out of bodies and taking risks that enabled maintenance of a sense of self. The prospect of only reflecting on functional deterioration, without opportunity to physically engage in everyday activity to the best of one’s ability, compromises the work of adaptation. These findings challenge us to look beyond physical symptom palliation and psycho-spiritual support as endpoints in either aiding or hindering adaptation to functional decline.

**Abstract number:** P277

**Abstract type:** Poster

**Concealed in the Ordinary: The Extraordinary Nature of Participation at the End-of-Life**

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**Aims:** To develop an understanding of everyday priorities for people experiencing functional decline at the end-of-life.

**Methods:** Ten patients with end stage cancer were interviewed in their homes. Participants had an Australian Karnofsky Performance Status Score between 50 to 70 and ages ranged from 51 years to 95 years. Perspectives were sought on their experiences of disrupted embodiment and functional decline and how these changes affected their day to day lives. Interviews were recorded, transcribed verbatim and analysed guided by Colaizzi’s methods. Transcripts were mapped against the conceptual frameworks of embodiment (Gadow, 1982, Leder, 1990) and occupation (Kielhofner, 2008).

**Results:** Participants experience inexorable fatigue that compromises ability to do everyday activities. Initially more complex activities, such as working, driving and leisure pursuits, are abandoned as available energy is channelled into personal needs. As exhaustion consumes even component parts of an activity like standing from a chair simply cease to be achievable - they no longer can. These changes result in feelings of frustration, anxiety, anger and guilt. Disrupted function also disrupts relationship with time as deteriorating bodies dictate new routines. The absence of familiar routines is disorienting and participants experience living in limbo. Loss of meaning experienced in the absence of familiar routines is ameliorated somewhat by retaining aspects of routines wherever possible.

**Conclusion:** When restoration of function becomes increasingly unattainable, inability to participate is distressing and frustrating. Conversely, ability to successfully engage in valued and essential activities, albeit modified, is deeply satisfying. Existing models of rehabilitation that focus on restoration of function do not meet the needs of these participants. An alternative model of habilitation that emphasises optimising skills and abilities that remain should be considered.
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Symptom Management in Primary Care: An Ethnographic Study of the Community Nursing Role

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Aims: Pain and other physical symptoms remain prevalent in the palliative care population, and outcomes are not always optimal. Assessment, monitoring, medicines management, evaluation and collaboration are key nursing roles that may have a positive impact. Whether and how nurses enact these roles is not well understood. This study aimed to investigate the role of the community nurse in palliative care provision, with a particular focus on observational exploration of their role and practice in providing patient care.

Methods: A longitudinal qualitative ethnographic design, comprising observation of community nurse/palliative care patient/carer encounters over time, and post observation interviews with patients, carers and nurses. Patients were sampled from 12 community team caseloads across three primary care organisations. Observations and interviews were audio-recorded and transcribed. Iterative data analysis comprised familiarisation, coding and categorisation using techniques of constant comparison to generate typologies of concepts. The study received all necessary ethics and governance approvals.

Results: 17 nurse/patient encounters were observed (n=11 patients, 8 nurses) with 23 post observation interviews (11 nurse, 12 patient/carer). The discussion of physical symptoms, especially pain, formed the core of each observed encounter. Nurses primarily focused on medicines management (dose, frequency, suitability), other approaches to symptom management were infrequent. Nurses were skilled at using informal conversational assessment styles, but the non-use of formal assessment tools could narrow the range of issues assessed. Nurses discussed the complex interplay between physical, psychological and social symptoms, but this was not always reflected in care.

Conclusion: The meaning attached to participation in everyday activities at end-of-life is concealed by the ordinariness of everyday activities and the ordinariness of everyday clinical work. It is imperative we look for the unspoken meanings attached to everyday activities as inability to participate contributes to existential suffering. It challenges us to look beyond palliation of physical symptoms as an end in itself and consider how palliation enables active participation in essential and valued everyday activities.

Abstract number: P278
Abstract type: Poster

What Factors Are Associated with Spiritual Well-being among Patients Receiving Palliative Care in South Africa and Uganda?

Selman L.1, Harding R.1, Higginson I.1, Agupio G.2, Dinat N.3, Downing J.4, Gwyther L.5, Gyseels M.6, Ikin B.7, Mashao T.8, Mcdaniel B.9, Mmoledi K.3, Moll T.10, Speck P.1, Encompass Collaborative

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Background: Although spiritual care is a core component of palliative care (PC), there is little evidence to guide services in this domain, especially in sub-Saharan Africa.

Aim: To identify factors associated with spiritual well-being (SWB) among PC patients in South Africa and Uganda, to facilitate the identification of patients at risk of spiritual distress.

Methods: A mixed-methods study design incorporated 1) a survey using the APCA African Palliative care Outcome Scale (A-POS) and Spirit 8, and 2) qualitative interviews with patients and spiritual care providers (SCPs).

1) Multiple and logistic regression analyses were used to identify clinical/demographic factors and PC-related problems associated with A-POS peace and life worthwhile and Spirit 8 spiritual well-being.

2) Thematic content analysis explored statistical findings and reasons for SWB/distress.
Results:
1) 285 patients were recruited (mean age 40, 80% HIV+). Better scores on A-POS ‘ability to share’ and ‘help and advice for your family to plan for the future’ were associated with better scores on all SWB variables. Time under care and inpatient care were positively associated with ≥1 variable. Worry and pain were negatively associated with ≥1 variable. Gender, age and diagnosis (HIV vs. cancer) were not significantly associated with SWB.
2) 72 patients (mean age 45, 60% HIV+) and 21 SCPs were interviewed.

Funders: Halley Stewart Trust

Abstract number: P280
Abstract type: Poster

Self-reported Symptom Burden in Prevalent Haemodialysis Patients in South-West Ireland

Lowney A.C., Lowney E.L., Murphy M., O’Brien T., Casserly L., Plant W.D.

Background: Life expectancy for many ESKD (End Stage Kidney Disease) patients is similar to, or worse than, that with common cancers. Maintenance dialysis therapy may offer a survival advantage but often fails to restore health or maintain quality of life (QOL).

Objectives: This cross-sectional observational study aims to characterise the subjective health-related QOL of patients with ESKD undergoing maintenance haemodialysis.

Methods: Following ethical approval, a validated clinical tool - the EQ5D was administered to prevalent haemodialysis patients in three haemodialysis units. It captures health-related QOL with endpoints in 5 domains. A Visual Analogue Scale (VAS) records the respondent’s self-rated health on a vertical scale where the endpoints are labelled ‘Best imaginable health state’ and ‘Worst imaginable health state’. Response rate was 89% (n=200). Data was analysed using SPSS.

Results: The most commonly reported symptoms are detailed below. Mean age was 63.61 ± 15.58. Median age was 66 (range 24-91).

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Reporting n (%)</th>
<th>[Frequency (n)] x [Score]</th>
<th>Scoring 3-4 n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weakness</td>
<td>148 (74%)</td>
<td>297</td>
<td>40 (20%)</td>
</tr>
<tr>
<td>Poor mobility</td>
<td>112 (56%)</td>
<td>212</td>
<td>36 (18%)</td>
</tr>
<tr>
<td>Pain</td>
<td>98 (49%)</td>
<td>248</td>
<td>34 (17%)</td>
</tr>
<tr>
<td>Difficulty</td>
<td>97 (49%)</td>
<td>189</td>
<td>24 (12%)</td>
</tr>
<tr>
<td>Sleeping</td>
<td>97 (49%)</td>
<td>189</td>
<td>19 (10%)</td>
</tr>
<tr>
<td>Drowsiness</td>
<td>97 (49%)</td>
<td>183</td>
<td>18 (9%)</td>
</tr>
<tr>
<td>Itching</td>
<td>97 (49%)</td>
<td>183</td>
<td>18 (9%)</td>
</tr>
</tbody>
</table>

Gastrointestinal symptoms were less frequently reported. Restless legs (45%) and anxiety (42%), were also common.

Conclusions: This structured clinical evaluation demonstrates the burden of uncontrolled symptoms in the maintenance haemodialysis population. It supports the internationally observed trend of greater integration of renal and palliative care services. Descriptive data such as these will inform strategies for integrated management protocols.

Abstract number: P281
Abstract type: Poster

Health-related Quality of Life in Prevalent Haemodialysis Patients in South-West Ireland

Lowney A.C., Lowney E.L., Murphy M., O’Brien T., Casserly L., Plant W.D.

Background: Life expectancy for many patients with ESKD (End Stage Kidney Disease) is similar to, or worse than, that with common cancers. Maintenance dialysis therapy may offer a survival advantage but often fails to restore health or maintain quality of life (QOL).

Objectives: This cross-sectional observational study aims to characterise the subjective health-related QOL of patients with ESKD undergoing maintenance haemodialysis.

Methods: Following ethical approval, a validated clinical tool - the Palliative Outcome Scale (POS-S Renal) was administered to prevalent haemodialysis patients in three haemodialysis units. This scores 0-4 for severity of 17 symptoms, experienced in the previous week. Response rate was 89% (n=200). Data was analysed using SPSS.

Results: The summary findings indicate a particularly significant disruption of the ability to perform usual Activities of Daily Living. Median VAS was 68 (IQR 50-80). Whether co-morbidity data and symptom burden
correlate significantly with these findings is the subject of ongoing research.

<table>
<thead>
<tr>
<th>Domain</th>
<th>No Problem</th>
<th>Some Problems</th>
<th>Severe Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>80 (41%)</td>
<td>111 (57%)</td>
<td>5 (3%)</td>
</tr>
<tr>
<td>Self-care</td>
<td>136 (71%)</td>
<td>41 (21%)</td>
<td>16 (8%)</td>
</tr>
<tr>
<td>Usual Activities</td>
<td>77 (40%)</td>
<td>74 (38%)</td>
<td>42 (22%)</td>
</tr>
<tr>
<td>Pain/Discomfort</td>
<td>92 (48%)</td>
<td>72 (38%)</td>
<td>28 (15%)</td>
</tr>
<tr>
<td>Anxiety/Depression</td>
<td>118 (61%)</td>
<td>63 (32%)</td>
<td>12 (6%)</td>
</tr>
</tbody>
</table>

**[Results]**

**Conclusions:** This structured clinical evaluation demonstrates the burden of ESKD and renal replacement therapy on QOL. The challenge facing clinicians is to select an individualized management strategy that offers patients the best QOL at all stages of their illness.

**Abstract number:** P282
**Abstract type:** Poster

**Bioimpedance Analysis as a Parameter of Cachexia in Head and Neck Cancer Patients**

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**Objective:** Bioimpedance analysis (BIA) is an established procedure to get information about the nutritional status of cancer patients. Is the phase angle of BIA a relevant marker to monitor the cachexia of a head and neck cancer patient? **Methods:** Between 2009 and 2011 we have performed BIAs in 66 male patients with head and neck cancer. 27 (41%) were still under follow-up observation, 39 (59%) of the patients had already died. We analyzed the first and the last measurement of bioimpedance of each patient. All BIAs were performed with biacorpus RX4000 (MediCal GmbH, Karlsruhe, Germany).

**Results:** The group of living patients has shown following shifts from the first to the last evaluation point: BIA phase angle from 4.8° to 5.2°, body mass index (BMI) from 23.6kg/m² to 23.6kg/m², body cell mass (BCM) from 25kg (9.0-37.0) to 26.5kg (15.0-42.0). In contrast, the died patients have shown the following shifts from the first to the last evaluation point: BIA phase angle from 4.2° to 3.7°, BMI from 24.3kg/m² (14.7-33.1) to 22.4kg/m² (14.2-30.0), BCM from 21.9kg (10.0-35.0) to 18.5kg (5.3-26.6).

**Conclusions:** BIA phase angle and the calculated BCM seem to be good markers to report the nutritional status of head neck cancer patients.

**Abstract number:** P283
**Abstract type:** Poster

**Comparison of Weight Loss and Risk of Malnutrition in Patients with Inoperable and Operable Pancreatic Adenocarcinoma**

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**Background:** Weight loss (WL) is a well-recognized characteristic of patients with pancreatic cancer (PC). WL may reflect a condition of cancer cachexia; a multifactorial syndrome of a combination of altered metabolism and reduced food intake that fluctuates over time. Patients with inoperable PC are regarded to have a high incidence of cachexia with reports that above 80% have lost weight upon diagnosis. Data on WL for patients with resectable disease is limited. Study aim was to describe and compare WL and risk for malnutrition at diagnosis in two groups of patients with verified pancreatic adenocarcinoma, one with inoperable and one with resectable disease.

**Methods:** This study was part of a large prospective project on PC in which all PC patients were consecutively enrolled and systematically followed every month until death. Measures related to nutritional status included body mass index, percentage WL, MUST (Malnutrition Universal Screening Tool) and the patients’ own estimate of overall food intake compared with normal intake.

**Results:** 190 patients with pancreatic adenocarcinoma were evaluated. Eighty-nine (47%) patients had inoperable (locally advanced or metastatic) disease and 101(53 %) had resectable disease. Mean ages in the two groups were 68 (SD 9.6) and 64 (SD 11.2) years, respectively. 19% of the patients with inoperable disease had had stable weight the last 3-6 months prior to diagnosis, while 18% had lost >10% weight. The group with resectable disease, however, reported significantly less weight loss; 37 % with stable weight (p< 0.05), and 16% had lost >10%, According to the MUST criteria, 27% of patients with inoperable disease were classified as being at risk of malnutrition compared to 20% of patients with resectable disease (ns).

**Conclusion:** More patients with inoperable PC have lost weight prior to diagnosis compared with those with resectable PC. However, the number of patients at risk of malnutrition seems to be equal in the two groups.
Qualitative Research on the Meaning the Health Professionals Ascribe to Rare Symptoms

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¹Associazione Cespi, Torino, Italy, ²AOU San Giovanni Battista della Città di Torino, Oncological Network of Piedmont and Aosta Valley, Torino, Italy

For health professionals the term *rare-symptoms* represents an area of doubtful interpretation, both for the meaning that the adjective *rare* assumes and because the term can qualify a symptom and its treatment. Beside this, such a definition can bring about a corollary of clues that may affect the treatment, evidence-based or non-conventional.

**Primary objective:** To bring knowledge and discussion in the Palliative Care Departments of Piedmont and Aosta Valley on the following items:

- a) the rarity of the symptom is due to a real infrequent manifestation or to a poor assessment, detection and reporting?
- b) Do exist symptoms, not widely acknowledged in literature, which occur on a recurring basis in the daily practice?
- c) How much does the frequency affect the perception of the severity of the symptom?
- d) There may be a possible interpretation of the meaning of “rare symptom”?

**Tools and methods:** Qualitative study, phenomenological, multicentric. Running and analyzing focus groups, we intend to interview senior physicians and nurses working in palliative care units, in order to agree on the definition of rare sign/symptom and draw up a list of infrequent symptoms accordingly to the terms agreed. The qualitative analysis of the focus groups will be carried out using the program N-Vivo.

**Expected outcomes:** Identify descriptors of rare signs/symptoms according to the practical experience of health professionals working in palliative care units. For each sign-symptom will be identified the fallout on the quality of life, on the treatment (pharmacological and/or not), and the monitoring procedures. The study is ongoing and the results will be available from January 2012.

**Funding:** Oncological Network of Piedmont and Aosta Valley

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Parenteral Nutrition Survey

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**Aim:** The role of parenteral nutrition (PN) in patients with incurable cancer and malignant bowel obstruction (P-IC-BO) remains controversial in current practice and according to available guidelines (e.g., ESPEN). A recent systematic literature review (Nestor, abstract ESPEN 2011) identified reports lack of evidence for patient populations, practices and outcomes of PN in P-IC-BO. The new consensual cancer cachexia classification (Fearon, Lancet Oncol 2011) may support decisions on patient populations potentially experiencing clinically relevant functional and subjective outcomes. We aim to investigate current practice of PN.

**Methods:** Cross-sectional, internet-based survey of clinicians (nutrition, oncology and/or palliative care) fulfilling defined inclusion criteria (substantial clinical involvement in PN of P-IC-BO). Demographics and general opinions about PN will be collected from excluded participants. The contents of the survey were developed by clinical and academic experts in palliative cancer care and cancer cachexia. Comprehensive case-vignettes explore participants’ practice about decisions for and goals of PN, their current practice (e.g., application, monitoring, setting), and outcomes. Finally information is requested about available practice guidelines, availability issues, and other. The analysis of categorical and open questions will be descriptive, group comparisons (e.g., professions, countries, high vs low PN-users) will apply t-test or Mann-Whitney U test, respectively. We expect a response rate of 50% from the selected groups from ESMO (ESMO-designated centers of integrated oncology & palliative care), MASCC (nutrition working group), and ESPEN (special interest groups PN and cachexia); from EAPC 10%.

**Results:** First results are expected in December 2011. Further results will be ready to be presented in June 2012.

**Expected impact:** Our data will allow to catalyze data-driven consensus processes leading to updated, multi-professional guidelines.
Prediction of Survival in Advanced Cancer Patients and the Intensity of Symptoms


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**Aim:** To assess the prognostic value of the intensity of symptoms for survival in hospitalized advanced cancer patients using a patient-reported questionnaire.

**Patients and methods:** Between 2008 and 2011 intensity scores on symptoms of 307 patients were prospectively assessed with the Utrecht Symptom Diary (USD), a patient-reported symptom questionnaire. Patients were divided into 3 groups, namely tumor-, symptom and terminal palliation. Daily 13 symptoms are scored on a 11-point numeric rating scale as part of regular care. The relationship between symptom intensity scores and survival time in days was examined using Kaplan-Meier statistics and uni- and multivariate Cox regression analyses.

**Results:** None of the symptoms was statistical significant as predictor in survival time at the univariate Cox regression analysis. The symptoms anorexia and asthenia seem to show a trend: an increase of the intensity of those symptom scores show a decrease of survival time. Multivariate Cox regression analysis shows the three different stages of palliative care as independent prognostic factor for survival. There was no improvement of the model when intensity of symptom scores was included.

**Conclusion:** No symptom intensity score reached the statistical significance as a predictor in survival time. Different dimensions in the symptoms anorexia and asthenia need more exploration in relation to other symptoms and variables. Also more exploration is needed to establish the optimal cut-off points on symptom intensity in relation to prognosis. Clinical experience confirms the need for further research on these subjects.

Prevalence, Treatment and Impact of Death Rattle: A Systematic Literature Review

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**Background:** Death rattle is a phenomenon in dying patients surrounded by a lot of uncertainty. The uncertainty concerns its prevalence in specific diseases, possible causes, usefulness of interventions and its impact on patient and caregivers. We performed a systematic review of published papers that contain empirical data on these issues.

**Method:** We systematically searched PubMed, EMBASE, CINAHL, PsychInfo and Web of Science. All English papers containing data on prevalence of death rattle, possible interventions for death rattle and impact of death rattle on caregivers (nurses, doctors, volunteers, family) were included.

**Results:** In total 35 articles were included in this review, of which 25 reported on prevalence of death rattle, 18 articles reported on possible interventions for death rattle, 8 (of these 18) also studied effectiveness of these interventions, and 10 dealt with the impact of death rattle. There is a wide variation in reported prevalences (12-92%, weighted mean 44%). Possible interventions are administration of anti-muscarin drugs, suction, repositioning, explanation of the symptom to relatives, diminishing artificial hydration, or sedation. Only administration of anti-muscarin drugs (7 articles) and diminishing of hydration (1 article) have been studied for effectiveness. These studies are mainly of poor quality due to design or sample size. Evidence to support the use of a specific anti-muscarin drug is lacking. Comparative studies have not been able to show differences in effectiveness between interventions. More than one third of patients experience death rattle despite medical treatment. The number of relatives who reported distress about death rattle ranged from 42% to almost 80%. Relatives were mainly worried about possible suffering of the patient. Several studies recommend more communication and explanation by healthcare workers. There is a need for prospective research which compares the effectiveness of medication and other interventions.

Polytherapy in Patients with Advanced Cancer- The Importance of Pharmacokinetic Interactions

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1Poznan University of Medical Sciences, Palliative Medicine Chair and Department, Poznan, Poland, 2Poznan University of Medical Sciences, Department of Pharmacology, Poznan, Poland

Drug-drug interactions are among multiple factors that may significantly affect the treatment in advanced cancer patients (pts), resulting in inadequate symptom control or toxicity.

**Aims:** to analyze drugs taken on a regular basis by the pts of palliative care in-patient unit, in respect to their potential of causing significant pharmacokinetic interactions.

**Methods:** Careful literature review was followed by the retrospective analysis of drugs used systemically in 100
in-patients. Potential pharmacokinetic interactions resulting from changes in the activity of CYP 450 isoenzymes and/or glycoprotein P (GPP), an efflux transport protein, were identified.

**Results:** Pts (mean age 68 years) were administered 1-13 (median 7) drugs for symptom control and treatment of concomitant conditions. A total of c.40 drug-drug combinations considered to be of potential clinical significance were determined. Combination of a strong opioid and/or benzodiazepine, metabolized by CYP 3A4 in a significant manner (fentanyl, oxycodone, methadone, midazolam, clonazepam, alprazolam and clorazepate), with an inhibitor (ciprofloxacain, fluconazole, midazolam) or inducer (dexamethasone or carbamazepine) of this enzyme system, was found in 90 pts. Opioids- substrates of GPP (morphine, fentanyl, oxycodone and methadone) were used concomitantly with GPP inhibitors (a proton pump inhibitor, amiodarone, spironolactone or haloperidol) or dexamethasone, an inducer of this protein, in 39 and 47 pts, respectively. Tramadol and oxycodone were delivered together with CYP 2D6 inhibitors (selective serotonin reuptake inhibitors, amiodaron, haloperidol and/or metoclopramide) in 17 pts.

**Conclusions:** The study demonstrates that the advanced cancer in-pts are treated with the combinations of drugs, which may potentially produce pharmacokinetic interactions. Further studies, evaluating the clinical significance of these interactions, with focus on opioids, benzodiazepines, and steroids, are awaited.

**Abstract number:** P289  
**Abstract type:** Poster  
**Nutritional Evaluation in an Acute Care Palliative Medicine Unit**  
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1Cleveland Clinic Taussig Cancer Institute, Nutrition Therapy, Cleveland, OH, United States, 2Cleveland Clinic Taussig Cancer Institute, Department of Solid Tumor Oncology, Harry R. Horvitz Center for Palliative Medicine and Supportive Oncology, Cleveland, OH, United States

**Introduction:** Malnutrition is common but under-diagnosed. We did a retrospective evaluation of nutritional status in a Palliative Medicine Program (PMP). Nutrition therapy assessments by a registered dietician (RD) and physician electronic medical record notes were reviewed.

**Methods:** Consecutive nutritional assessments for 2009 were reviewed. RD used a standard assessment tool with 6 criteria for malnutrition. At least two criteria had to be present. Physician notes were reviewed to evaluate whether malnutrition was reported and/or graded.

**Results:** 213 nutrition therapy consults were reviewed for 116 patients. Median age 65 years (range 19-94); 57% male; 84% cancer diagnosis. Most common cancers were gastrointestinal 26%, genitourinary 26%, respiratory 16%. 78% had metastatic disease. 147 (69%) nutrition therapy consults were eligible for RD assessment. Most often requested by physician/physician assistant (51%), dietetic technician (21%), or nurse (18%). Of the 147 nutrition therapy consults, most 99 (67%) identified malnutrition per RD assessment; 55% moderate/severe. Most often malnutrition was noted by unintentional weight loss (59%), low nutrient intake (58%), and low serum albumin (54%). Weight loss was severe in 68%. 60% of physician notes did not document nutritional status; 28% reported moderate to severe malnutrition.

**Conclusions:** Moderate to severe malnutrition was highly prevalent. Local and national diagnostic criteria are imprecise. Weight loss, nutrient intake, and albumin level were equally important to RD nutritional assessment. Nutritional assessment by physicians was inadequate. Better recognition and diagnosis of malnutrition is needed for improved patient care and earlier nutritional intervention.

**Abstract number:** P290  
**Abstract type:** Poster  
**Palliative Care in Parkinson Disease**  
*Miyasaki J.1, Mancini-Ferretti D.1, Fox S.H.2, Moro E.1, Long J.1, Lang A.E.1, Chen R.1, Ghoche R.3, Strafella A.1, Arshinoff R.4*  
1University of Toronto, Department of Medicine, Toronto, ON, Canada, 2University of Toronto, Department of Medicine, Toronto, PE, Canada, 3University of Toronto, Department of Family Practice, Toronto, ON, Canada, 4University of Toronto, Toronto, ON, Canada

**Aim:** To establish the benefit of palliative care in Parkinson disease.

**Methods:** An interdisciplinary team of physicians, nurses, care coordinators and spiritual counselors have provided care to over 100 patients. Patients and caregivers were assessed using Hoehn and Yahr staging, Unified Parkinson Disease Rating Scale (part III) (UPDRS), modified Edmonton Symptom Assessment Scale (ESAS-PD), Montreal Cognitive Assessment (MOCA) and Caregiver Strain Index.

**Results:** The mean Hoehn and Yahr stage is 5 (bedbound unless aided). Mean UPDRS was 40/108(17-80). The mean MOCA was 14/30. A modified ESAS-PD mean was 52/140. Pain improved significantly. Following one visit, the 3 month score was 41 (P=0.04). Improvement magnitude is similar to cancer patients receiving palliative care. Caregiver Strain improved from 14 to 10 (p = 0.04). Twenty-two patients died (16 at home, 1 in a palliative care unit, 5 in acute hospital). Cause of death was aspiration pneumonia (17/22), sepsis (2) and “died in their sleep” (3). Updated data will be presented.

**Conclusion:** We conclude that palliative care in Parkinson disease can effectively address previously unrecognized
symptoms, improve patients report of wellbeing and help patients and families realize their home as their place of death.

Abstract number: P291
Abstract type: Poster
Is Adequate the Clinical Prognostication of Palliative Patients By Professionals Who Take Care of Them?

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Aims: To assess whether the PaP Score (PS) by doctors and nurses in palliative cancer patients (PC) is adjusted with the real survival and to examine whether there are differences in applying the scale between different professionals taking into account the clinical experience (CE) and its training in palliative care (TP).

Methods: We collected demographic and clinical data of patients over a period of 6 months. Patients were evaluated by a doctor and a nurse in the first three days after admission. We included only patients with recent analytic. Patients were classified according to the PS for both professionals (probability of survival at 30 days in A> 70%, B 30% to 70%, C < 30%). Qualification was collected (years of practice in palliative care). We conducted follow-up patients in the first and third month.

Results: In a total of 159 patients, 63 were excluded, 81% (51) because lack of recent analytic) leaving a total of 97 patients (61%), 64% males, median age of 78 years (range: 22-101). CE and TP of physicians was very similar (N: 8, 64%; 7-10 years experience in PC and 100% of TP), is not the case with nurses (N: 17, 23% with 1-3 years experience in PC and 92% of TP). The PS performed by doctors / nurses, N: 7 / 23 in group A, with a median survival of 49 days in both, N: 51/51 in group B with a median survival of 28/22 days, N: 29/23 in group C with a median survival of 7 / 6 days. By comparing the PS by various professionals there is a high concordance, no significant differences. There is a trend without reaching statistical significance to overestimate the survival of patients in group A by nurses with less clinical experience and there is a tendency to underestimate the survival of patients in group C by physicians with more experience.

Conclusions: The PaP Score by doctors and nurses is consistent with the actual survival without significant differences among professionals. There is a greater degree of convergence predicted in group B.

Abstract number: P292
Abstract type: Poster
Quality of Life as a Prognostic Indicator of Survival in Advanced Cancer Inpatients

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Background: Quality of life (QoL) predicts survival in advanced cancer patients; this relationship has not been explored in the palliative care setting.

Methods: This is a retrospective cohort study. 162 inpatients in palliative wards of 6 hospitals in South Korea were followed until death. Patients reported QoL using the European Organization for Research and Treatment Quality of Life Questionnaire Core 15 for Palliative Care (EORTC QLQ-C15-PAL), a palliative care specific instrument, translated into Korean and validated. Patients reported additional symptoms using the MD Anderson Symptom Inventory-Korean (MDASI-K). During the same encounter, physicians documented Palliative Performance Scale (PPS) and Eastern Cooperative Oncology Group performance status (ECOG). Correlations between EORTC QLQ-C15-PAL, MDASI-K, PPS, and ECOG were assessed. Survival analyses were performed using Cox proportional hazard models.

Results: Physician-reported PPS and ECOG predicted survival (hazard ratio [HR] 2.174 and 1.900 respectively; p< 0.001). From the EORTC QLQ-C15-PAL, patient-reported Physical Functioning (PF), correlated with PPS and ECOG (r=0.633 and -0.631, respectively; p< 0.001), and predicted survival (HR 1.332; p=0.011). All domains of the EORTC QLQ-C15-PAL also significantly correlated with interference items of MDASI-K, further confirming construct validity of the EORTC QLQ-C15-PAL in our population. Individual symptoms from the EORTC QLQ-C15-PAL predictive of survival were nausea-vomiting (HR 1.279; p=0.025) and constipation (HR 1.434; p=0.002).

Conclusions: Patient-reported Physical Functioning of the EORTC QLQ-C15-PAL was an independent prognostic factor in advanced cancer inpatients, providing retrospective evidence that patient reported QoL is predictive in a palliative care population. Patient-reported nausea-vomiting and constipation may be independent prognostic symptoms. It is interesting that total QoL was not predictive. Prospective study is warranted.
Background: Constipation is often inadequately assessed and underdiagnosed in patients with advanced cancer. Many studies use patient-reported constipation as an outcome. Our aim was to determine the association between patient-reported constipation, physician’s assessment of constipation (yes or no and rated 0-10), and objective assessment of constipation by modified Rome III criteria among advanced cancer outpatients.

Methods: Patients with advanced cancer attending a supportive care clinic were screened. Constipation was assessed using the modified Rome III criteria, patient’s reports (yes or no and rated 0-10; 10 = worst possible symptom), and physician assessments.

Results: 100 patients were enrolled and 50/100 (50%) patients met the modified Rome III criteria for constipation. Disagreement between Rome III criteria and the patient report (yes/no) was found in 33 patients (33%) and between Rome III criteria and the physician assessment (yes/no) was found in 39 (39%). The best combination of sensitivity (0.84) and specificity (0.62) was found with score ≥ 3/10 for patient-reported constipation.

Conclusions: We found a high frequency of constipation. The limited agreement with modified Rome III criteria suggests that a patient’s self report as yes or no is not useful for clinical practice. Patient’s self-rating ≥ 3 on a 0 to 10 scale seems to be the best tool for constipation screening among this population. More research is needed to identify the best way to assess constipation in advanced cancer patients.

Abstract number: P294
Abstract type: Poster

Four Item Fatigue Scale (FIFS): Validation by the Brief Fatigue Index (BFI)

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Background: A FIFS questionnaire was tested to substitute the BFI and capture changes in fatigue along with ICD-10 criteria.

Methods: Cancer patients completed BFI and FIFS in random order. FIFS included 4 questions:
1. Do you have fatigue (weariness, tiredness): never, sometimes, usually, or always
2. On a scale of 0-10 (0: no fatigue 10: severe fatigue) how would you rate your fatigue (weariness, tiredness) now: none, mild, moderate, severe
3. What is the level of your fatigue (weariness, tiredness) now: mild, moderate, severe
4. Is your fatigue (weariness, tiredness) over the last day: worse, the same, better

One week later, both BFI and FIFS were completed in opposite order. 65 patients were needed for 80% power for Spearman correlation of ≥ 0.7. Bonferroni corrections were made for multiple variables; p < 0.0035 was significant.

Results: 65 patients completed ICD-10, BFI and FIFS day 1 and 7. Spearman correlation between FIFS and BFI was 0.7 (0.52-0.88) day 1, 0.73 (0.55-0.91) day 7, 0.59 (0.38-0.80) for change over time. BFI score correlated with ICD10-1, 3, 7, and 10B. Regression analysis showed day 7, BFI correlated with ICD10-1, 7, and 10; these disappear when adjusted for BFI on day 1. For changes in BFI from day 1 to 7, only ICD10-5 criteria is significant and drops out of the model when adjusting for day 1 BFI. For FIFS, ICD10-7 and 10 were significant and persist after adjustment for baseline FIFS score. FIFS and BFI correlated well. FIFS substituted for BFI. Certain ICD-10 items better correlated with fatigue severity. With regards to survival differences, no statistically significant relationship with BFI score or FIFS score on either day 1, day 7 or the change between two occurred.

Conclusions: FIFS is valid for CRF. Certain ICD-10 items better predict fatigue severity. ICD-10 criteria need further validation. The FIFS was not indicative of survival rate.

Abstract number: P295
Abstract type: Poster

The Revised Spanish Version of the Edmonton Symptom Assessment System (ESAS-r): First Psychometric Analysis Involving Advanced Cancer Patients

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Background: The Revised Spanish Version of the Edmonton Symptom Assessment System (ESAS-r) is a tool to determine the symptom severity of patients with advanced cancer. New scales are needed to capture changes in symptoms over time.

Methods: 100 patients with advanced cancer were evaluated with the ESAS-r. The Revised Spanish Version of the Edmonton Symptom Assessment System (ESAS-r) is a self-administered, multidimensional, and multidisciplinary tool that assesses symptoms such as pain, fatigue, anxiety, depression, appetite, nausea, shortness of breath, and overall distress. The Revised Spanish Version of the Edmonton Symptom Assessment System (ESAS-r) is a self-administered, multidimensional, and multidisciplinary tool that assesses symptoms such as pain, fatigue, anxiety, depression, appetite, nausea, shortness of breath, and overall distress.

Results: The Revised Spanish Version of the Edmonton Symptom Assessment System (ESAS-r) was validated in a sample of 100 patients with advanced cancer. The Revised Spanish Version of the Edmonton Symptom Assessment System (ESAS-r) showed good internal consistency (Cronbach's α = 0.92) and test-retest reliability (intraclass correlation coefficient = 0.85). Spearman's correlation coefficients were calculated between baseline and follow-up ESAS-r scores.

Conclusions: The Revised Spanish Version of the Edmonton Symptom Assessment System (ESAS-r) is a valid and reliable tool for use in clinical practice with patients with advanced cancer.
The Edmonton Symptom Assessment System (ESAS) is an instrument widely used in palliative care for the assessment of symptoms in advanced cancer patients. The instrument has been validated in different languages, including Spanish. An revised version (ESAS-r) of the instrument was developed by Watanabe, et al. (2010).

**Objectives:** To develop the revised Spanish version of the ESAS (ESAS-r), and to examine psychometric properties of the tool.

**Method:** Based on the original English version, a group of experts obtained a Spanish version of ESAS-r and applied it to a group of advanced cancer patients. Patients completed the ESAS and the ESAS-r and were asked for the perception of the instruments. Psychometric properties of the ESAS-r were analysed: intra-rater reliability; internal consistency; and discriminant validity.

**Results:** 66 patients from Spain and Guatemala participated in the survey. ESAS-r was significantly easier to understand and easier to complete than ESAS. Significantly, more patients preferred ESAS-r (47%) than the ESAS (15%, p< 0.0007). About reliability, we found good internal consistency (Cronbach’s Alpha of 0.86) with interrater correlations of the two versions between 0.71-0.94. ESAS-r discriminate between inpatients and outpatients (Mann-Whitney U test, p=0.02) and between best and worst palliative performance status (Spearman’s Rho, pain, asthenia, drowsiness, anorexia, wellbeing, p< 0.01).

**Conclusion:** The ESAS-r is a valid instrument with adequate psychometric characteristics. This version is preferred by advanced cancer patients. The new Spanish version of the ESAS (ESAS-r) can therefore replace the previous version.

**Abstract number:** P296

**Abstract type:** Poster

**Does the Implementation of Edmonton Classification System for Cancer Pain Improve our Practice?**

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The usefulness of the Edmonton Classification System for Cancer Pain (ECS-CP) in clinical practice remains to be proved.

**Aims:** To assess the adequacy of analgesia prescribed on initial hospital-based palliative care consultation using ECS-CP.

**Methods:** Prospective data concerning all advanced cancer patients referred during a 6-month period. Patient demographics, analgesic medication (including breakthrough pain (BP) rescue, pain adjuvants and opioid consumption), current pain intensity, and ECS-CP were recorded at admission. Prescribed analgesia at first visit was registered as a routine. Pain Management Index (PMI) and parenteral morphine equivalent daily dose (MEDD) before (T0) and after the initial (T1) intervention were calculated. The use of 1) a strong opioid as BP rescue, 2) adjuvant drugs for neuropathic pain and 3) around-the-clock strong opioid to manage severe pain were additional quality indicators.

**Results:** 52% of our sample (n=176, median age 67y, 51% female and 1 out of 3 hospitalized) had a digestive tumor and was receiving cancer treatment. 126 (72%) had a pain syndrome, 31 (18%) severe pain at the moment, 85 (48%) neuropathic features and 113 (64%) BP episodes. At first visit prescriptions were significantly changed (classes of analgesics, MEDD, adjuvants and nonpharmacological modalities). A negative PMI was more prevalent before consultation (35% vs. 16%, p < 0.001). Neuropathic pain was significantly associated, on multivariate logistic regression analysis with negative PMI [OR 5.5 p< 0.001 (T0) and OR 3.8 p=0.02 (T1)]. Age, severe pain and delirium didn’t prove to remain significant covariates for negative PMI after intervention. Around-the-clock use of a strong opioid to manage severe pain was the only indicator that had not significantly improved after visit.

**Conclusion:** Results point out that the improvement in the appropriateness of the analgesic care delivered can be, at least in part, explained by a systematical use of ECS-CP tool.

**Abstract number:** P297

**Abstract type:** Poster

**Assessment of Discomfort in Patients with Cognitive Failure in Palliative Care**

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1Portuguese Institute of Oncology, Palliative Care Unit, Porto, Portugal, 2Unidade de Saúde Local de Matosinhos, Matosinhos, Portugal, 3Hospital de S. Sebastião, Santa Maria da Feira, Portugal

**Objective:** At our palliative care unit when patients cannot report their symptoms we use to assess their state of comfort/discomfort by the overall observation of the patients. We record the observation as “signs of discomfort - yes or no”. With this study we try to assess the validity of this method.

**Methods:** Patients were assessed, on a convenience basis, for cognitive failure with the Consciousness Scale for Palliative Care and the Confusion Assessment Method, and those with cognitive failure were included. Patients were assessed by 2 doctors and 7 nurses. Two of them observed simultaneously each patient recording independently if the patient showed signs of discomfort or not. A third
element asked the patients who maintained some capacity to communicate if they had any discomfort at that moment. For inter-rater agreement the Cohen’s kappa coefficient was used and the raw agreement measures for the proportions of positive and negative agreement. The sensitivity, specificity, the positive and negative predictive values were also calculated.

**Results:** Between May 12th and October 10th 112 observations were made in 60 patients. The kappa coefficient was 0.60; the proportion of positive agreement was 0.63 and the proportion of negative agreement 0.97. The sensitivity was 26% (CI 95%: 0.16-0.36), the specificity was 96% (CI 95%:0.95-1.00), the predictive positive value was 86% (CI 95%: 0.78-0.93) and the negative predictive value was 75% (CI 95%: ).

**Conclusion:** This method for the assessment of discomfort in patients with cognitive failure has a good coefficient of agreement between raters, with a very good proportion of negative agreement. The specificity is also very high as well as the predictive positive value. However, the sensitivity was only of 26%, meaning that many cases of discomfort were missed. Therefore, more research is needed on this particular aspect of patients’ assessment.

**Abstract number:** P298
**Abstract type:** Poster

**Adaptation of the EORTC QLQ-C15-PAL Quality of Life Questionnaire to the Polish Clinical Setting in Patients with Advanced Cancer**

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**Aims of the study:** Quality of life (QOL) assessment is critically important in patients with advanced cancer. The purpose of the study was to adapt the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - Core 15 - Palliative Care (EORTC QLQ-C15-PAL) to Polish and to evaluate its psychometric properties in patients with advanced cancer.

**Patients and methods:** There were two measurements performed at baseline and after seven days of the symptomatic treatment. The EORTC QLQ-C15-PAL concurrent validity was established by the Pearson’s correlation coefficients with the modified ESAS (Edmonton Symptom Assessment System), the Karnofsky Performance Status (KPS) and the Brief Pain Inventory - Short Form (BPI-SF). Reliability was assessed using the alpha-Cronbach coefficients and the Spearman correlation coefficients of the baseline and of the second measurement of the EORTC QLQ-C15-PAL items.

**Results:** One hundred and twenty nine patients completed the questionnaire at both QOL measurements. The concurrent validity revealed numerous significant correlations of the EORTC QLQ-C15-PAL pain scale with the BPI-SF, EORTC QLQ-C15-PAL symptom items with the modified ESAS and EORTC QLQ-C15-PAL functional scales with KPS scores. High alpha-Cronbach and standardised alpha-Cronbach values were found for both functional (0.830 - 0.925; 0.830 - 0.932) and symptom scales (0.784 - 0.940; 0.794 - 0.941) of the EORTC QLQ-C15-PAL, respectively. Spearman correlation coefficients between the first and the second measurement were significant (p < 0.0001) for all EORTC QLQ-C15-PAL items.

**Conclusions:** The Polish version of the EORTC QLQ-C15-PAL is a valid and reliable tool recommended for QOL assessment and monitoring in patients with advanced cancer.

**Abstract number:** P299
**Abstract type:** Poster

**Process of Developing a New Tool to Assess the Psychosocial Needs in Patients at the End of Life (ENP-E)**

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**Background:** To provide palliative care to the dying patient as effective as possible is necessary to know which aspects of psychosocial nature that can contribute to well-being of these patients, and for this, we must have reliable assessment tools, simple and specific for use in this area.

**Aim:** Developing an instrument for assessing the psychosocial needs of the patient at the end of life (ENP-E) attending in a palliative care unit.

**Methods:** To develop the ENP-E was performed the following steps:
1) literature review (Medline, Cochrane, PsychInfo and Psyclict),
2) focus group meeting with palliative care professionals,
3) discussion about the dimensions and most relevant topics in the psychosocial field of palliative care,
4) description of the most important indicators of each dimension and development by consensus the questions on each dimension and
5) revision of the instrument elaborated by external experts in palliative care.

**Results:** 18 questions were developed, belonging to the following dimensions: emotional, coping, communication / relationships and spirituality. The format of answer of each question was performed using a numerical scale of 0-10 and the application form is administered by health professional. Currently being conducted a pilot study with 30 dying patient to analyze the adequacy of this new tool. Afterwards, we will analyze the psychometric properties in a final sample of 150 dying patients.

**Conclusions:** We believe that the scale ENP-E provides a better understanding of psychosocial needs at patient at the end of life, and will provide a more comprehensive palliative care, specific, individualized and effective.

**Acknowledgements:** The Study was supported, in part, by the “Programa para la Atención Integral a Personas con Enfermedades Avanzadas y a sus Familiares”. Obra Social La Caixa, Spain.

**Abstract number:** P300

**Abstract type:** Poster

**Detection of Emotional Distress Scale (DME) for Screening of Emotional Distress in Advanced Cancer Patients**

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**Background:** Advanced cancer patients usually have high levels of psychological distress. To alleviate this suffering is necessary to evaluate it. The Detection of Emotional Distress scale (DME) has been proposed as a screening tool for emotional suffering in advanced cancer patients.

**Aim:** To determine the psychometrics properties and the clinical usefulness of DME in advanced cancer patients attended in a Palliative Care Unit (PCU).

**Methods:** 105 advanced cancer patients admitted in five Catalan PCUs were enrolled, giving their consent. DME was administered to assess emotional distress. Interviews were conducted by psychologists and physicians previously trained to administer this tool. Hospital Anxiety and Depression Scale (HADS) and Emotional Thermometer (ET) were also administered. The study was approved by the Clinical Research Ethic Committee.

**Statistical analysis:** A standard descriptive analysis was carried out. To assess the correlation between scales’ scores, chi-square correlation coefficient was calculated. Through Receiver-Operating Curve (ROC) a cut-off point was determined to provide the best sensitivity and specificity curve to establish the points needed to assume emotional distress through DME.

**Results:** Mean age of patients was 67.3±12.6 years. 50 were men. The main primaries cancer diagnoses were: lung-16.2%, colon-15.2%, pancreas-13.3% and breast-11.4%. 58.3% had moderate to severe emotional distress, similar to other scales such as ET. The cut-off point for DME evaluated by ROC suggests that the best ROC curve is a value of ≥ 9, with specificity and a sensitivity of 75%. It was found a positive and significant statistically intraclass correlations with ET and HADS.

**Conclusions:** DME is a useful tool that makes it easier to identify emotional distress in advanced cancer patients attended in PCUs. Our results suggest the systematic use of DME in hospitalized patients as a screening tool to determine specific psychological intervention.

**Abstract number:** P301

**Abstract type:** Poster

**Using Mini-Mental State Examination (MMSE) to Screen for Delirium in Elderly Patients with Hip Fracture**

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for detecting delirium, as measured by the Confusion Assessment Method (CAM), in elderly patients with hip fracture.

**Methods:** The sample included 364 elderly patients with hip fracture admitted to two hospitals in Oslo, Norway. Patients were screened daily from admission to hospital through the sixth postoperative day (or until discharge). To evaluate the psychometric properties of the MMSE scale, we used Mokken’s non-parametric latent trait model for unidimensional scaling, as implemented in MSP5 for Windows.

**Result:** The MMSE scale has good psychometric properties in the patient group, however, neither the recommended MMSE cut-point of 24, logistic regression on the MMSE total score, nor the five items selected by the stepwise logistic regression procedure, can identify delirium satisfactorily when compared against a delirium diagnosis by CAM.

**Conclusions:** Our study indicates that the MMSE did show quite satisfactory psychometric properties in measuring cognitive impairment. However, the MMSE seems to be a poor predictor of delirium as diagnosed by CAM in patients with hip fracture.

**Abstract number:** P302
**Abstract type:** Poster

**Optimizing Service Provision Using Qualitative Methodology to Facilitate the Assessment of Palliative Care Teams**

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**Background:** This work is a part of a larger project to evaluate Palliative Care (PC) service provision by validating a resource questionnaire from which to create a Team Assessment Tool.

**Aims:** To find out whether we can evaluate managerial, material and human resources with qualitative methodology. To establish questionnaire composition validity, content and criterion with collaboration from Home Care and Hospital Teams professionals.

**Methods:** A discussion group was selected as the suitable method, with a set group of questions. A discourse was obtained from the professionals’ own experiences. The selection was a heterogeneous multiprofessional and interdisciplinary group fulfilling accessibility and representation criterion (4 Gordon’s questions criterion).

We contacted them by telephone and email. Two discussion groups were held in March and October 2011 and were made up by 6 and 8 professionals each one: Physicians, Nurses, Psychologists, Social Workers and Spiritual Agents, who agreed to be recorded during the session. The research items proposed were based on the Resources Questionnaire designed by the Regional Coordinator to establish and assess PC Services Provision. The 2 interviews were transcribed, selecting the most representative verbatims.

**Results:** The analysis result allowed us to group the information in various topic points: geographical dispersion of human resources, professional and personal motivation, “psycho-emotional help” for professionals, patient’s integrated approach, teams homogeneity, social services budget, caregiver support, PC teams’ relationships, workloads, managerial support and teams’ future.

**Conclusions:** This effort is a good a reliable source of information for the Regional Coordinator to improve PC services and map out reliably its process and understand how professionals perceived needs and views on service development in their region. It also provides a working base to help determine appropriate service infrastructure.

**Abstract number:** P303
**Abstract type:** Poster

**An Evaluation of the Access to Opioid Medication in Europe (ATOME) Six-country Workshop**

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**Background:** In September 2011, the Access to Opioid Medication in Europe (ATOME) project held the first of two Six-Country Workshops in Bucharest, Romania. The workshop was attended by regulatory and law enforcement authorities and opinion leaders or ‘champions’ among healthcare professionals; these experts formed ‘country teams’ undertaking legislative and policy reviews, leading to recommendations that will facilitate access for all patients requiring treatment with medicines controlled under international drug conventions. People attending the first workshop were from Bulgaria, Cyprus, Greece, Turkey, Serbia, and Slovenia.

**Aim:** To evaluate the impact of the workshop on the experiences, beliefs, and potential concerns of participants.
in relation to controlled medicines for pain and symptom management.

**Method:** A pre-workshop questionnaire and a post-workshop questionnaire were distributed to all participants at the beginning and at the end of the workshop. Questions focused on
(a) barriers and opportunities in gaining access to controlled medicines in their respective country,
(b) knowledge and attitudes regarding access to controlled medicines as a fundamental human right, and
(c) participants’ evaluation of the workshop.

**Results:** A total of 16 participants completed both pre- and post-workshop questionnaires (answers ranged from ‘considerably’ to ‘not at all’): 15/16 reported that their knowledge about accessibility of controlled medicines ‘had been enhanced’ by attending the workshop; 12/16 reported that their attitudes in relation to the accessibility of controlled medicines ‘had been changed’ by attending the workshop; and 15/16 reported that their personal expectations of the workshop ‘had been realised’.

**Conclusion:** The results of the workshop evaluation suggest that the first ATOME six-country workshop was successful in enhancing participants’ knowledge and in changing their attitudes in relation to the accessibility of controlled medicines.

**Abstract number:** P304
**Abstract type:** Poster

**Use of a New Screening Tool to Determine the Frequency of Emotional Suffering in Advanced Cancer Patients Visited at Home**


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**Background:** Detection of Emotional Distress scale (DME) is a new screening tool of emotional distress in advanced cancer patients (pts) validated in hospitalized pts; a cut-off of 9 or more means emotional suffering.

**Aim:** To describe the frequency of emotional distress and other emotional characteristics in advanced cancer pts visited at home.

**Patients and methods:** Observational descriptive study. Advanced cancer pts visited by 2 homecare teams (nurses, physicians, social worker) were included. DME was administered in the 1st and 3rd visit. External signs of emotional distress were also recorded as well as the need of psychological support considered by the team. Dementia and last days of living were exclusion criteria for DME assessment. The study was approved by the local Ethic Committee and pts signed the consent.

**Results:** 115 pts were assessed, mean age 72.9±13.2 years. 67.8% were men. Main cancer diagnoses were lung-23.5%, colon-8.7% and liver-7.8%. Mean time since diagnosis was 24.3±33.5 months. 59% had metastasis. Barthel index at 1st visit was 55.7±25; 67.8 had no cognitive impairment and 12% had psychiatric disorders. DME in the 1st visit was administered in 84 pts (mean 10.8±4.6 [0-20]). 76.8% of those pts had emotional distress; 40.9 % signs of emotional suffering: facial expression 38.3%, isolated pts 7%, asking for attention 7%, sleep disorders 7%. At 3rd visit DME was completed in 34 pts, with a mean of 9.26±3.8; 56% had emotional distress and 14.8% signs of emotional suffering. In those 34 pts that completed both DME-evaluations, the same level of emotional distress was presented (p=0.893). The team considered that in 53% of cases they would refer pts to the psycho-oncologist if they were available at homecare.

**Conclusions:** In this study there is a high frequency of emotional distress in the 1st visit with no statistically differences in the follow-up. These results make recommendable the specific intervention of psycho-oncologists in homecare.

**Abstract number:** P305
**Abstract type:** Poster

**5 Year Experience of the Clinical Use of the Edmonton Classification System for Cancer Pain**

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**Background:** Our service has completed the Edmonton Classification System for Cancer Pain (ECS-CP) on initial assessment of all patients since 2005.

**Aim:** To review our experience with the ECS-CP and to assess whether the ECS-CP identifies changes in patient demographics over the 6 years of use, and is linked to patient need and resource use.

**Methods:** Over 75% of referrals to the Pain and Palliative Care service at Peter MacCallum Cancer Centre are initiated...
for pain management. Between May 2005 and June 2011, 2705 patients, (2837 separate visits) were assessed by the ECS-CP. Of these, 2216 patients (2346 visits) also had a single Edmonton Symptom Assessment Scale (ESAS) assessment on the same day.

**Results:** The median age of the 2705 patients at first assessment was 63.1 years. In the 2796 visits when an ESAS was completed, 1440 (52%) had a pain intensity Numerical Rating Scale (NRS) of ≥4. Among the 2837 visits when ECS-CP was completed, on 35% of visits, patients reported a neuropathic pain syndrome (Ne), 54% incident pain (Ii) and 31% psychological distress (Pp).

Increase in pain reporting: in 2005 the percentage of patients reporting neuropathic pain, incident pain, and psychological distress was 37%, 57%, 21%, and these rose by 2011 to 51%, 70%, 51%, respectively. The ESAS pain score and ECS-CP was associated with the number of contacts. Those with ESAS pain ≥4 experienced a mean number of contacts of 13.3, compared with those with lower pain scores’ average number of 9.5 contacts. Further work will determine if these individual ECS-CP features are associated with overall survival.

**Conclusions:** Complex pain is increasingly common among patients in a palliative care setting at a cancer hospital and more likely to have an increased number of service contacts. Further analysis will determine whether complex features predict for other aspects of resource allocation.

**Abstract number:** P306  
**Abstract type:** Poster  
**Evaluating an Holistic Assessment Tool for Palliative Care Practice**

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Holistic assessment is a complex process which presents challenges for palliative care practice. The need for effective and structured assessment of patients’ needs has been identified. Assessment tools can be used to assess needs and inform care planning. This study discusses the importance of evaluating the use of such tools in practice.

**Method:** A mixed method research design was employed and comprised of four stages.

- **Stage 1:** overview of the theoretical literature;  
- **Stage 2:** Analysis of piloted holistic assessment tool (n=132);  
- **Stage 3:** Focus groups with pilot leads and assessors (n=10) to explore usability, applicability and potential service barriers and facilitators towards implementation and  
- **Stage 4:** Assessor questionnaire (n=24) evaluating the structure, format and presentation of the holistic tool.

**Findings:** The tool did appear to enable health professionals to identify and gain an understanding of the needs of the patients, specifically in relation to the patients’ physical health care needs. Analysis of the tool documentation revealed that 59 (68.8%) responses had discussed preferred priorities of care with the patient; however focus groups comments revealed participants had concerns around this. The use of clinical prognostic indicators was ambiguous: the first phase indicated that professionals had considered a prognostic clinical indicator for the patient as an action, whilst other strands indicated that there were questions around health care professional’s knowledge and perceived usefulness of clinical prognostic indicators. Positive aspects of the tool included: it was easy to understand; not time consuming & captured the needs of individuals. Negative aspects included it was repetitive and the experience of assessors and training required consideration.

**Conclusion:** The health care professionals considered that holistic assessment was being carried out in practice and the completion of this tool was duplication and repetition.

**Abstract number:** P307  
**Abstract type:** Poster  
**‘Feeling at Peace’ and ‘Feeling that Life Is Worthwhile’ – Items to Measure Spiritual Well-being in Sub-Saharan Africa**

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**Background:** Spiritual well-being is a core outcome of palliative care and yet it is often neglected in clinical practice. Spiritual outcome measures are useful for screening and essential for clinical audit but guidance on the choice of measures is lacking, particularly in sub-Saharan Africa.

**Aim:** To explore how two indicators of spiritual well-being (feeling at peace and feeling that life is worthwhile) are interpreted by patients receiving palliative care in South Africa and Uganda, to inform spiritual assessment and care.
Methods: Cognitive interviews were conducted with patients receiving palliative care at 5 services (4 in South Africa, 1 in Uganda) to ascertain the meaning of ‘feeling at peace’ and ‘feeling life is worthwhile.’ Interview transcripts were translated into English. Thematic content analysis was conducted to determine interpretations of the concepts.

Results: 72 patients were interviewed in 7 languages (mean age 45, 67% women, 60% HIV+). Feeling at peace was interpreted according to 4 main themes: perception of self/world (e.g. acceptance of illness, feeling calm); relationship to others (openness, supportive relationships); spiritual beliefs; health and healthcare (e.g. pain and symptom control). Feeling life is worthwhile was interpreted according to 3 main themes: perception of self/world (e.g. being positive); relationship to others (e.g. feeling valued); identity (e.g. independence). Peace raised everyday concerns (e.g. socioeconomic worries), while life worthwhile was related to meaning and purpose; both were also interpreted in relational terms.

Conclusions: The concepts of feeling at peace and feeling that life is worthwhile are well understood by patients in South Africa and Uganda and are interpreted holistically. The concepts measure different aspects of spiritual well-being and, subject to further testing, may be useful for screening and assessment in this population.

Funders: Halley Stewart Trust

Abstract number: P308
Abstract type: Poster

Hospital Deaths or Acute Hospital Deaths?
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Objectives: Deaths occurring in hospital is an increasingly important indicator for End of Life (EOL) care. We explore variations in hospital deaths with emphasis on cancer deaths and those occurring in acute hospital settings.

Methods: Data on cause and place of death were extracted from Office for National Statistics (ONS) annual mortality files for years 2007-2009. Hospital deaths as a proportion of all deaths were calculated for Local Authorities (LAs) in England. Similar analyses were then repeated for deaths occurring in acute hospitals.

Results: Over half (57%) of all deaths from any cause occurred in hospital with LA variations ranging between 43% (Cambridge) and 75% (Waltham Forest). 45% of deaths from cancer occurred in hospital. It was not possible from available data at National level to sub-categorise hospital types. One reason for this is the organisational nature of many secondary care providers e.g. many NHS Hospital Trusts have multiple locations and render secondary care services within the community. This makes it impossible to estimate the proportion of deaths that occurred in acute hospital settings at a National level. Local knowledge of the South West (SW) region however showed the proportion of hospital deaths is reduced from 52% to 43% for acute hospitals with SW LAs varying between 22% (Penwith) and 59% (Christchurch) in acute hospitals. This reduction is also reflected in cancer deaths from 43% in all hospitals to 32% in acute hospitals (varies between 14% - Penwith and 60% - Christchurch).

Conclusions: Place to place variations exist in the proportion of hospital deaths in England. The differences shown between hospital and acute hospital deaths reflects a need to better define the indicator to support ongoing efforts to reduce numbers of people near EOL that are unnecessarily admitted to die in acute hospitals.

Abstract number: P309
Abstract type: Poster

The Reliability of the PAINAD in Patients Receiving Palliative Sedation for Intractable Pain
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Research aims: Palliative sedation is used to alleviate refractory symptoms at the end of life. Although intractable pain is a known indication to start sedation, assessment of pain under sedation and thus the evaluation of this intervention remains difficult. The aim of the present study is to evaluate the reliability of an observational scale for pain in terminally ill patients receiving palliative sedation.

Methods: In two hospices, nineteen terminally ill patients receiving palliative sedation for intractable pain were assessed using the Pain Assessment IN Advanced Dementia (PAINAD) - a five item scale (scores per item 0-2) - to measure pain. The PAINAD was filled out independently by two nurses prior to and within one hour after start of sedation. The Interclass Correlation coefficient (ICC) was used to analyse the inter-rater reliability between observations.

Results: Patients received intermittent (57.9%) or continuous sedation (42.1%) with midazolam. The diagnosis at admission was cancer in 84.2%, non-cancer in 10.5% or both in 5.3%. A total of forty paired assessments were performed by 42 individual nurses. The median sum score for both assessments was 1.0, indicating mild pain. We found an ICC of 0.528 (95% CI: 0.263-0.719) for the item ‘breathing’;
Abstract number: P310
Abstract type: Poster

The Prognostat - A Multi-site Study of a New Tool for Survival Prediction in Palliative Patients

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Aim: To test a new non-invasive prognostic tool for cancer and non-cancer palliative patients
Method: Multi-site prospective study testing several factors: Functional status (PPS), Clinician prediction of survival (CPS); Illness trajectory (Australian phases); Demographic factors; Charlson Comorbidity Index; and, several symptoms found significant in other studies. Laboratory results were not included. Outputs include KM-graph and nomogram. Also focus group qualitative analysis regarding the practical utility of the tool was conducted.
Results: 495 patients from 3 sites and including PCU, home and ward consultations. The 4 strongest predictors are CPS, PPS, primary disease and illness trajectory. Age, gender and location of care were significant and lessor factors included delirium, dyspnea, tiredness and weight loss. Charlson index was not significant and eliminated from final model along with appetite and skin breakdown. Harrell C-stat was 0.79. Focus groups indicated the tool to be easy, quick and most clinicians would use the tool, especially the nomogram table format versus the KM- or nomogram graphs.
Conclusion: The Prognostat is a quick and easy tool for survival prediction in patients already deemed palliative. It affirms predictive several variables in other prognostitic tools but adds illness trajectory and questions the relevance of Charlson index in advanced stage patients. The nomogram calculator table was the preferred method for clinical use.

Abstract number: P311
Abstract type: Poster

Accuracy of Serial Clinical Survival Estimates in Advanced Cancer Patients

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It remains unclear if prognostic accuracy significantly changes after performing serial estimates.
Aim: To compare physicians’ accuracy on clinical prediction of survival (CPS) at admission and at visit 3.
Methods: Prospective observational cohort study with all cancer patients enrolled in a hospital-based palliative care program for a 9-month period; routinely collected patient data (age, gender, diagnosis, current anticancer treatment, Karnofsky Performance status) and CPS (in weeks) at admission, and then, on each visit, by the same practitioner were recorded; dates of patients’ deaths were obtained from hospital records or public death registries; prognoses were accurate when the difference between the predicted survival (PS) and actual survival (AS) was between -1 and 1. Values less than -1 were pessimistic prognostic errors and those greater than 1 were optimistic.
Results: 106 (45%) patients from the initial 239 patients’ cohort (median age 67, 48% male, 50% digestive tumors, 45% under cancer treatment, median follow-up time 46 days) survived until visit 3. A median of 17 days (range 2-120) elapsed between admission and visit 3. At study end 26% of patients seen at visit 3 were alive. 5 of them outlived their initial prognosis, yielding 84 patients for analysis. Prognoses at admission and at visit 3 were accurate in 32 (38%) and 37 (44%) of cases, over-pessimistic in 27 (32%) and 24 (29%) and over-optimistic in 25 (30%) and 23 (27%), respectively. The propensity towards more accurate CPS at visit 3 failed to reach significance (p=0.08). Accuracy was inversely related to AS at visit 3, but not at admission. At visit 3, physician’ likelihood to err was directed related to longer PS [per week OR 1.5 (95% CI 1.2, 1.8) p< 0.001] but unrelated to the length of patient-doctor contact.
Conclusion: A third seriated CPS wasn’t significantly more accurate than the first one. A better doctor’ knowledge of the patient didn’t seem to have adversely affected our estimates.

Abstract number: P312
Abstract type: Poster

Survival Implications of Consciousness Level in Advanced Cancer Patients
Wakefulness, one of the dimensions of consciousness was barely studied as a prognostic factor.

**Aim:** To explore the usefulness of the Consciousness Scale for Palliative Care (CSPC) as a prognostic tool in cancer patients.

**Methods:** We prospectively followed all cancer patients enrolled in a hospital-based palliative care program for a 9-month period. Patient characteristics (age, gender, diagnosis, current cancer treatment and performance status), presence/absence of delirium (Confusion Assessment Method-CAM) and wakefulness, using the six-level CSPC scale were recorded on admission. Kaplan-Meier curves were used to compare the survival of patients according to their CSPC score. A Cox proportional model was fitted to all covariates.

**Results:** 239 patients (median age 67, 48% male, 50% digestive tumors, 45% under cancer treatment, 63% outpatients, median follow-up time 46 days) were enrolled. At admission, 159 patients (67%) were spontaneously alert (level 1), 41 (17%) awaked when called by name and kept alert (level 2), 22 (9%) awaked but felt asleep during conversation (level 3), 9 (4%) reacted without eye contact (level 4), and 8 (3%) didn’t react to voice (level 5 or 6). The log-rank test for the equality of survival curves showed significant differences among the curves over the six CSPC levels (p< 0.001). However, pair-wise log-rank tests for adjacent pairs failed to show significantly differences between level 3, 4 and 5 survival curves. The median survival was 93 days (95% CI 67, 119) for spontaneously alert, 2 days (95% CI 1, 3) for those who didn’t react to voice and 17 days (95% IC 7, 27) for the remainder. In a multivariate model CSPC score and current cancer treatment (but not delirium) remained significant in hazard regression. The higher the CSPC score the higher the hazard ratio. The log-rank test for the equality of survival curves showed significant differences among the curves over the six CSPC levels (p< 0.001). However, pair-wise log-rank tests for adjacent pairs failed to show significantly differences between level 3, 4 and 5 survival curves. The median survival was 93 days (95% CI 67, 119) for spontaneously alert, 2 days (95% CI 1, 3) for those who didn’t react to voice and 17 days (95% IC 7, 27) for the remainder. In a multivariate model CSPC score and current cancer treatment (but not delirium) remained significant in hazard regression. The higher the CSPC score the higher the hazard ratio. The log-rank test for the equality of survival curves showed significant differences among the curves over the six CSPC levels (p< 0.001). However, pair-wise log-rank tests for adjacent pairs failed to show significantly differences between level 3, 4 and 5 survival curves. The median survival was 93 days (95% CI 67, 119) for spontaneously alert, 2 days (95% CI 1, 3) for those who didn’t react to voice and 17 days (95% IC 7, 27) for the remainder. In a multivariate model CSPC score and current cancer treatment (but not delirium) remained significant in hazard regression.

**Conclusion:** Wakefulness assessed with CSPC was an independent prognostic factor in our patients.

**Abstract number:** P313

**Abstract type:** Poster

**Palliative Care-related Problems among Cancer- and Non-cancer-Patients: Differences in Prevalence and Intensity. A Systematic Review of the Evidence**

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**Background:** Palliative care is care-giving not only for persons with cancer but also for persons with non-cancer life-limiting diseases. Fact is that there is a greater amount of research concerning symptom control among cancer patients. This complicates getting an overall view of the burden intensity of the multi-dimensional palliative care-related problems palliative patients may experience. The main research question of this review is: what is the prevalence and intensity of palliative care-related problems among advanced cancer- and non-cancer patients? The scoped palliative patients were: end-stage patients suffering from: cancer, AIDS, heart disease, chronic obstructive pulmonary disease, renal disease, neurological diseases (MS and MND), Parkinson disease and dementia.

**Methods:** A systematic review search of the following three medical databases was executed: Medline, EMBASE and PsycINFO. Three groups of keywords were used to search for eligible papers. These keywords were developed via the literature exploration of 12 palliative care- and oncology-textbooks, existing palliative care-related problem studies and the analysis of the reviews of Simms and Solano. Inclusion- and exclusion criteria were created based upon the main research question of the review. The data of the studies were extracted to a predesigned headed table and finally analysed into a prevalence summary table. The PRISMA 2009 Flow Diagram was used to visualize the results of the review process.

**Results:** The search resulted in finding 4670 hits after removing 1784 duplicates. The final number of included papers will be available in November 2011. The summary of the prevalence figures will be presented using minimum and maximum as ranges.

**Conclusion:** One of the biggest challenges the review already discovered was dealing with the methodological heterogeneity within the included studies. This had complications for the analysis of the prevalence data and for the discussion section of the review.
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Aim: In patients (pts) with advanced, incurable cancer, anticancer treatment may alleviate cancer-related symptoms, but their systematic monitoring is scarce. Prior work suggested the feasibility of real-time, longitudinal monitoring using the E-MOSSIC software installed in handheld computers given to patients by the nurses before oncologists’ visits, resulting in the longitudinal monitoring sheet (LoMoS). There is little current evidence documenting the effects of electronically support symptom assessment in this setting. We aim to test in a phase III setting the effectiveness of the E-MOSSIC intervention.

Methods: Randomized phase-III trial of eligible oncologists initiating a new outpatient chemotherapy (expected tumor size response rate ≤20%, solid tumors, minimal symptom burden). All pts complete weekly the E-MOSSIC assessment (1. ESAS, optional symptoms [0-3], estimated nutritional intake, 2. body weight, KPS, 3. medications for pain [e.g., MEDD, NSAR], fatigue [e.g., methylphenidate], and cachexia [e.g., nutritional supplements, prokinetics]). Oncologists randomized to the intervention arm will get the immediately printed one-page LoMoS, the others none. Primary endpoint is the intra-patient difference of items 29 & 30 of EORTC-QiQ-c30 (SD predicted 20 points, clinical relevance 10) after 6 weeks. Secondary endpoints are a) patient-perceived patient-physician communication (Fogarty, JCO 1999), b) symptom burden over time, and c) oncologists’ symptom management performance [defined thresholds of symptoms requiring immediate actions {e.g., pain ≥7} and diagnostic, pharmacological, or counselling activities [“sympec” chart review].

Due to clustering structure comparison of different outcomes of treatment arms is analysed using mixed models, considering predefined covariates. Sample size is 264 patients for 168 evaluable pts.

Results: by 10.2011 259 patients of physicians are enrolled; final analysis if expected by Q1/2012.

Aim: To assess the significance of serial PaP measurements on prognostication in advanced cancer.

Methods: Prospective observational cohort study concerning all cancer patients enrolled in a hospital-based palliative care program for a 9-month period; patient data [age, gender, diagnosis, current anticancer treatment, Karnofsky and Palliative Performance status (PPS), presence/absence of symptoms and recent (≤7 days) complete blood count - CBC] and expected survival (in weeks) at admission (V1), and then, on the next 2 visits (V2 and V3) were recorded, by the same practitioner. Dates of patients’ deaths were obtained from hospital or national records. PaP V1, PaP V2 and PaP V3 were retrospectively calculated.

Results: A total of 239 patients (median age 67, 48% male, 50% digestive tumors, 45% under active treatment, 63% outpatients, and median follow-up 30 days) were referred. Two patients (1%) at admission and 7 (7%) at visit 3 didn’t have CBC data. At study end 46 (19%) were alive. A median of 7 and 17 days elapsed between V1 and V2 and V3, respectively. PaP and PPS had significant effects on survival. PaP was significant in hazard of death at all time points, whereas a low (£30) PPS failed to significant at V2. For all 3 PaP measurements the Kaplan-Meier curves stratified patients into 3 groups (PaPA, PaPB and PaPC) each with a significantly different survival profile (log-rank test p<0.001). The 30-day survival were in PaPA groups 87% (V1), 94% (V2) and 85% (V3), in PaPB groups 45% (V1), 47% (V2), and 65% (V3) and in PaPC groups 14% (V1), 3% (V2) and 0% (V3). A “drop” into a more unfavorable group (i.e. from group A to group B/C or from group B to group C) on consecutive evaluations didn’t change survival significantly (log-rank p=0.56 at V2 and p=0.26 at V3).

Conclusion: Data suggest that serial PaP measurements may not be useful.

Abstract number: P316
Abstract type: Poster
Correlation between the Modified Edmonton Symptom Assessment Scale (ESAS-PD), the Health Utility Index and Quality of Life 15D Scale

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Aims: We sought to validate the ESAS-PD against the Health Utility Index, previously validated in advanced Parkinson disease (PD).

Methods: Thirteen consecutive patients from a tertiary care centre providing palliative care completed the ESAS-PD, Health Utility Index (HUI) 2 and 3 and the Quality of Life Questionnaire 15D. Demographic data including PD stage,
Towards a Standardized Method for Developing Quality Indicators for Palliative Care?

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Aims: In recent years, several studies have aimed at developing quality indicators for palliative care with, however, a large variety of methods being used. In the ‘Quality Indicators for Palliative Care’ study (Q-PAC study) we tried to work out a scientifically rigorous method to develop a comprehensive and valid quality indicator set, able to serve as a standardized method.

Methods and results: The followed method involved 4 phases. First, an extensive literature review was performed to identify existing international quality indicators, as well as relevant dimensions and themes for quality of palliative care. Second, the most important themes for quality of palliative care were withheld based on an expert panel scoring. Third, for the prioritized themes, quality indicators were scored by a different multidisciplinary expert panel for usability and necessity, in keeping with the RAND/UCLA-method, combining evidence with consensus among stakeholders. This panel included perspectives of caregivers and policy makers in palliative care, as well as of patients and next-of-kin. Fourth, the concept set is tested and evaluated in palliative practice for usability and feasibility. In this phase the indicators are translated into questionnaires presented to patients, next-of-kin and caregivers. To stimulate the acceptance and use of the indicators, stakeholders, including the national palliative care organizations, are involved throughout the whole project.

Conclusion: Our 4 phased indicator development resulted in a set applicable to all patients in all palliative care settings, includes patient and next-of-kin perspectives, and covers outcome, process, and structure indicators. The proposed method can contribute to a more standardized method for developing a set of quality indicators for palliative care, both meeting the required scientific rigor and creating a sound basis to achieve the comprehensiveness needed in a set of quality indicators for palliative care.
20% and investigations 10%. Eighty-six percent were known to the hospital palliative care team, 28% also had a community palliative care team. Twenty-four percent received chemotherapy during their last admission. Overall median time from chemotherapy to death was 33 days (min 1, max 1197). There was evidence of patients deteriorating and death was expected in 86%. Of those with an expected death, 67% were on the LCP, with the Patient’s Preferred place of death documented in 26%. Sixteen percent of all deaths were on the Critical Care Unit. Median length of stay was 11 days (min 0, max 49 days).

**Conclusion:** These preliminary results show the majority of dying patients were known to the hospital palliative care team, and the majority of patients expected to die were placed on the LCP. However improvements could be made in the documentation of preferred place of death earlier in a patient’s illness trajectory.

This audit was conducted with no funding.

**Abstract number:** P319  
**Abstract type:** Poster  
**Cancer Pain Management in an Outpatient Chemotherapy Department of Japan: A Preliminary Report Used the Pain Management Index and the Substantial Pain**

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**Background:** Patients with advanced cancer receiving out-patient chemotherapy have been increasing steadily in Japan. For preparation of a multicenter survey on cancer pain management in the setting, we needed a weekly report in an institution belonging to the regional cancer center hospitals (RCCHs) in our country.

**Method:** Our preliminary study was conducted in an ambulatory chemotherapy section of a hospital of RCCHs during a week in 2010. Consecutive 47 patients were interviewed or handed a questionnaire for self-writing by the nursing staffs of the division. To compare our result with the domestic or international data performed prior, we employed the before half of the Brief Pain Inventory, Japanese version (BPI-J: Uki, 1998), Pain Management Index (PMI, negative value corresponds inadequacy of physicians response along with WHO analgesic ladder in their analgesic prescription: Cleeland, 1994 ) and the classification of the substantial pain (patients with impaired ADL function rate their pain severity at the midpoint or above on a scale of 0-10: Cleeland, 1997).

**Results:** All surveyed patients responded perfectly (45 interviewed, 2 self-written); 47 was approximately 70% of whole registrants in the department at that point. Prevalence of cases with negative PMI value was 40.4%, and the weighted average of PMIs in whole subjects -0.4 +/- 1.1. The ratio of surveyees suffering the substantial pain reached 17.0% (8/47) in worst pain: 10.6% (5/47) in average one.

**Discussion:** First, feasibility and acceptability of our planning study was confirmed via this report. Second, we were able to compare our data with past domestic report on prevalence of negative PIM (70.7% by Okuyama in 2004); with prior report on the ratio of the substantial pain in western countries (61.7% by Cleeland in 1997; 59.9% by deWit in 1999).

**Abstract number:** P320  
**Abstract type:** Poster  
**Reconsidering relevance: A baseline review of prescribing patterns in an Irish inpatient palliative care unit**

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**Background:** There is a poorly developed evidence base and lack of high-quality research with regard to polypharmacy at the end of life. Even before admission to hospice for end of life care, prescribers can persist with evidence based guidelines prescribing for all treatable medical illnesses which can be expensive and of dubious benefit to patients in their final days or weeks (O’Mahoney D, Age and Ageing (2011)).

**Aims:** To determine the number and types of medications prescribed in patients who are admitted to a specialist palliative care unit over a six month period.

**Methods:** A retrospective chart review on all patient who died in the specialist inpatient palliative unit over a six month period (between April 2011 and September 2011) was conducted. Patient data was collected on the number and type of medications used in each patient on their admission to the palliative unit. Types of medications prescribed were also subdivided into categories to determine the most common classes of drugs in use in this population.

**Results:** We will present the results from a review of 174 patients who died over a six month period.

**Abstract number:** P321  
**Abstract type:** Poster  
**Development and Usability of a Technology-assisted Real-time Audit Tool for Community Palliative Care**

*Kamal A.H.1, Bull J.2, Kavalieratos D.1, Shang H.1, Roe L.1, Nortmann R.1, Lowery A.1, Kelly J.1, Downey W.1, Abernethy A.P.1*
Methods: Approaches to support quality assessment or audit in palliative care are not routinely available, especially in the community. Provider burden during data collection, issues of data interoperability, and concerns of clinical relevance remain significant barriers. In response, we aimed to develop and conduct usability testing of an audit tool to collect and report quality information at point of care in real time.

Aims: Approaches to support quality assessment or audit in palliative care are not routinely available, especially in the community. Provider burden during data collection, issues of data interoperability, and concerns of clinical relevance remain significant barriers. In response, we aimed to develop and conduct usability testing of an audit tool to collect and report quality information at point of care in real time.

Methods: In partnership with 4 community-based palliative care organizations in the United States, we conducted regular meetings to establish priorities for the audit tool. Using clinician feedback, we evaluated candidate lists for validated instruments, quality measures to incorporate, and effective reporting structures. Software usability testing was conducted using mock patient cases with 20 community providers to assess five standard usability outcomes: efficiency, memorability, learning ease, errors, and satisfaction.

Results: After completing a systematic review of all published quality measures, we developed a web-based tool, the Quality Data Collection Tool (QDACT), to inform 90% of all measures. It includes: validated instruments when available and instruments with face validity when validated ones are lacking; skip pattern logic to reduce provider burden; and, quarterly and ad hoc reports for feedback. Compliance with metadata standards and interoperability with large publically-available datasets was achieved. A variety of technology platforms met software usability criteria and matched the ease of paper forms; tablet computers were preferred. Time for QDACT completion was less than 15% of the total clinical consult duration. High satisfaction, ease of learning, and memorability alongside low error frequency were observed. Large-scale feasibility testing during real patient encounters is ongoing.

Conclusion: The QDACT is a usable system for audit and reporting in community palliative care.

Abstract number: P322
Abstract type: Poster
Audit of Potential Drug Interactions and Duplicate Prescriptions among Palliative Care Patients in an Acute Hospital
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Background: Drug interactions are the cause of approximately 20 - 30% of all drug side-effects, of which 70% need clinical attention and 1 - 2% is life threatening. Polypharmacy is well recognised in palliative care patients thereby increasing the potential risk of drug interactions and duplicate prescribing. Drug interactions in palliative care patients have been shown to have significant consequences in terms of pain management and delerium. This area has not been examined exclusively in palliative patients in the acute hospital setting.

Aims: In relation to the hospitalised palliative care patient population, to:
1. Establish the extent of polypharmacy and duplicate prescribing.
2. Determine prevalence and character of potential drug interactions along with possible risk factors.
3. Determine how Specialist Palliative Care (SPC) team involvement influences these parameters.

Method: Patient recruitment is prospective. The charts of 50 consecutive inpatients referred to SPC service in an acute hospital in Ireland are analysed. Drug charts are screened for drug interactions using Stockley’s Drug Interactions 9 software which classifies interactions by levels of severity and strength of scientific evidence. Drug class duplication is also recorded. The screening process occurs at two points: Point of referral to SPC service and one week later. If death or discharge occurs before this time, it is regarded as the second screening point. Data is analysed with Microsoft Excel and SPSS 12.

Results: Data collection ongoing. Pilot of 15 patients revealed 24 potential drug interactions in 6 patients. 60% classified as moderate severity. 50% of those drug interactions were associated with steroids and 17% with codeine and oxycodone. Drug class duplication was not prominent. SPC involvement had lower rates of drug interaction. Measures to support safe drug prescribing for the hospitalised palliative care patient need to be addressed.

Abstract number: P323
Abstract type: Poster
An Audit of the Multidisciplinary Management of Malignant Bowel Obstruction on an Oncology Ward in an Acute Tertiary Hospital
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Background: Malignant bowel obstruction is common in advanced cancer. It is frequently associated with a poor prognosis. Management is complex and requires multidisciplinary input.

Aims: The primary aim was to provide baseline information on key areas of malignant bowel obstruction management
for future auditing purposes. A secondary aim was to assess compliance with the current hospital guidelines for the medical management of this condition.

**Methods:** The medical notes for 32 admissions to the oncology ward of an acute tertiary hospital between 31st July 2009 and 1st August 2010 were reviewed. Data was entered onto a proforma. Descriptive statistical analysis was performed using SPSS.

**Results:** The majority of patients had advanced cancer with peritoneal metastases (n=28, 88%). Ovarian was the most common primary site (n=17, 57%). 15 patients (47%) were committed to a course of chemotherapy at presentation. Patients had symptoms of nausea (n=26, 81%), vomiting (n=26, 81%), abdominal pain (n=26, 81%) and altered bowel habit (n=27, 78%). Medications were administered via a continuous subcutaneous infusion in 19 cases (60%). A nasogastric tube was inserted in 10 cases (31%). Cyclizine was the most commonly used first-line anti-emetic (57%). Octreotide was used in 3 cases (9%). Treatment of persisting bowel obstruction included: chemotherapy (n=13, 41%), surgery (n=3, 9.4%), radiotherapy (n=1, 3%), stenting (n=5, 15%) and venting gastrostomy (n=1, 3%). 7 patients (22%) were commenced on parenteral nutrition. 27 patients (84%) survived to discharge and, of these, 20 (74%) were discharged home.

**Conclusion:** The results indicate that the presentation and nature of malignant bowel obstruction is heterogeneous and that treatment decisions vary widely. The current local guidelines are under review to promote more consistent management and to guide referral to important disciplines.

**Abstract number:** P324  
**Abstract type:** Poster  
**Patient Experience in the Hospice Setting - What Matters?**

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**Background:** Hospices provide often much-appreciated specialist palliative care for patients with life-limiting illnesses. Little, however, is known about how patients feel about their experience of hospices.

**Aims:** This study aimed to capture patients’ opinions of their experience of care in a large hospice organisation to better understand its strengths and weaknesses from the patient’s perspective.

**Method:** Data was collected through 30-minute, confidential, semi-structured interviews with both hospice in-patients and day therapy unit patients. Interviews were conducted by a professional independent of the organisation and unknown to patients, with subsequent thematic analysis of collected data.

**Results:** The majority of in-patients (87%) reported their admission to be for pain control, with (13%) citing ‘medication review’. However 64% of day patients regarded referral purely for social support and 36% for pain management. 59% of patients viewed hospices as places where people come to die. Almost all (97%) patients were referred by a healthcare professional, yet only 24% received written information about the hospice prior to their first visit. Over half (55%) were unaware of additional services offered by the hospice (e.g. complementary therapy, allied health professional review). 47% of in-patients identified boredom as a significant problem, compared with 14% of day patients. Most patients felt better (79%) and happier (90%) following referral.

**Conclusion:** Patients find hospice services beneficial in terms of self-described quality of life, and are generally satisfied with the service they receive. Communication, and patient perception and understanding, may be a particular issue, with a lack of both pre-referral and ongoing information provision, and an erroneous understanding of the function of hospices. Boredom can be a significant factor for hospice in-patients.

**Abstract number:** P325  
**Abstract type:** Poster  
**Venous Thromboembolism Prophylaxis in Specialist Palliative Care Units in Northern Ireland**

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**Aims:** Venous thromboembolism (VTE) is a major cause of mortality and morbidity in hospitalised patients and VTE prophylaxis (VTEP) is a clinical priority in the UK. The role of VTEP in specialist palliative care units (SPCU) has not yet been defined. The purpose of this audit was to assess VTEP practice in SPCUs in N. Ireland (NI).

**Method:** A retrospective chart review of 40 consecutive admissions with malignancy to 3 SPCUs in NI was performed. The audit standards were adapted from NICE (2010) guidance on VTEP for hospitalised ‘palliative patients’ stating that VTEP should be considered if potentially reversible acute pathology (PRP) is present with no contraindications, and not routinely offered to patients assessed to be dying.

**Results:** 117 case notes were reviewed (60 male, mean age 67). 11 patients receiving therapeutic anticoagulation were excluded. 106 were included, of whom 58% died during admission. 88% patients had 2 or more risk factors for
VTE, only 5% had their risk of VTE documented and 61% had no contraindications to VTEP. 15 patients were already on VTEP at admission and this was continued in 11. VTEP was newly commenced in 5% of admissions. 37 (35%) patients who had either PRP on admission or developed it while an inpatient, met NICE criteria for VTEP but did not receive it. No patients who were thought to be dying were commenced on VTEP. A decision regarding VTEP use was only documented in 12% of cases. No patients were documented to have received either verbal or written information regarding VTEP.

**Conclusion:** The role of primary VTEP in SPCU is unclear despite VTE risk being moderate or high in the majority of inpatients. VTEP is often continued but rarely initiated. 35% of patients met NICE criteria for VTEP but did not receive it. Documentation of risk and VTEP decisions needs to improve, as well as patient information on VTEP. This audit is prompting the development of a patient information leaflet and VTEP guidelines for SPCUs in NI.

**Abstract number:** P326

**Abstract type:** Poster

**New Developments in Quality Indicators for Palliative Care**

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**Background:** In 2007 an international systematic review by Pasman et al. (J Pain Symptom Manage, 2009) indicated that a number of quality indicators for palliative care were already developed, with most of them referring to outcome or process of care. Indicators concerning psychosocial and spiritual aspects of palliative care were scarce. The majority of publications lacked a description of feasibility and validity of the indicators.

With the boosting attention for quality indicators for palliative care, many initiatives and further developments of quality indicators were expected. We therefore considered it necessary to update the 2007 review.

**Aims:** To give a recent overview of published quality indicators for palliative care and observe whether new developments have been made, both in terms of the type and number of developed indicators, and of methodology.

**Methods:** Relevant publications were identified by a computerized search up to October 2011. Same databases (PubMed/Medline, Embase, CINAHL and PsycINFO) and search strategy from the original review were used. Publications describing development process or characteristics of quality indicators for palliative care were selected by two reviewers independently. Additionally either numerators and denominators or norms had to be derivable from the descriptions of the indicators.

**Results:** In addition to the 650 hits found by Pasman et al., we found 435 new hits. Compared to the 16 publications meeting inclusion criteria in 2007, we found 10 new publications meeting these criteria. Some new sets have been developed, while other sets have been tested further concerning validity and feasibility. The methodological characteristics of the indicators still varied considerably.

**Conclusion:** In the last 4 years, there has been a boost in the development and publication of quality indicators for palliative care. To accurately monitor the quality of palliative care, however, more detailed methodological specifications are still needed.

**Abstract number:** P327

**Abstract type:** Poster

**An Electronic Version of the LCP: An Opportunity to Facilitate Quality Control, Benchmarking and Research in the Dying Phase**

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**Background:** Providing high quality care is an important objective during a disease trajectory. The Liverpool Care Pathway for the dying patient (LCP) is an instrument that can be used to provide quality care in the dying phase. The LCP has been shown to enhance quality of care in the dying phase in several ways. The LCP is currently being implemented in a increasing number of care settings around the world. Data collected with the LCP can be used for the evaluation of quality of care, for benchmarking between settings, patient groups and countries, and also for research purposes. Aim of our project was to develop an electronic version of the LCP for primary use in daily practice with the ability to be used as an instrument for quality control, benchmarking and research in the dying phase.

**Method:** We developed an electronic version of the Dutch LCP. The premise for this version was that it could be used in every care setting, by every caregiver, independent of or connected to a preexisting digital patient record, meeting all national requirements for security, safety and privacy and with reasonable costs for use. In addition it was required that the program enabled quality control, benchmarking and altering of the instrument for specific research purposes.
Results: A non-commercial, open source, digitalized version of the Dutch LCP was developed. This web-based program has the ability to be connected to a local patient record or to be used as a program on its own. The program is linked to a national database where data is stored in a way that it cannot be traced back to a specific patient. From this database quality control and benchmarking is possible. Altering of this digital version is possible to suit specific needs of a care setting or to enable the gathering of research-specific data. This digital version of the Dutch LCP will also be available in English. The first study with use of the system and database is planned for spring 2012 and will focus on hydration.

Abstract number: P328
Abstract type: Poster

Advance Care Planning - Are We Good at Discussing the Issues in Specialist Palliative Care Units?

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Aims: To identify the quality of Advance Care Planning (ACP) discussions within a network of Specialist Palliative Care Inpatient Units in the Thames Valley Cancer Network, United Kingdom. To assess if these ACP discussions were communicated on discharge, to the key professionals involved in care.

Methods: A retrospective review of 15 patient records, who were discharged separately from five different Specialist Palliative Care Inpatient Units in early 2011.

Results: A total of 70 patient records were available for review and analysis. In over half the patients reviewed, there was some evidence of an ACP discussion. The communication of ACP discussions rarely included the out of hours medical and ambulance service.

Conclusion: The communication of ACP discussions to some key professionals involved in care could be improved on. The introduction of a standardised ACP tool within the Thames Valley Cancer Network, may improve the documentation and communication of an individual’s ACP discussion.

Abstract number: P329
Abstract type: Poster

Quality Improvement in Palliative Care: Implementation of Quality Indicators - Study Protocol

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Introduction: The need for palliative care is rising, now that the European population is ageing. Particularly vulnerable patient groups can benefit from palliative care. However, it is an intriguing question why available knowledge on palliative care is not used, even when there is evidence of its effectiveness in helping to solve problems. The IMPACT project (IMPlementation of quality indicators in PAlliative Care sTudy) aims to develop optimal implementation strategies to improve the organization of palliative care in Europe using quality indicators.

Methods: In February 2011, this EU funded 7th framework project started. Throughout the project, multiple methods (e.g. a literature study, systematic review, integrative review, interviews, focus groups) will be used to develop implementation strategies to improve palliative care and dementia care. Before and after the implementation of these strategies, quality indicators will be used to assess the organisation of palliative care and dementia care in 40 settings in England, Germany, Italy, Norway and The Netherlands.

Results: The results of IMPACT project will provide stakeholders and decision makers with useful tools to facilitate effective implementation of high quality palliative care and dementia care in different setting in Europe.

Discussion: The application of quality indicators for palliative care in a wide variety of settings addressing not only cancer patients but also patients with dementia on a European scale is unique. Making one set of quality indicators developed for two diseases offers the opportunity to benefit from the knowledge gained in two fields that are segregated until now, but that have a lot in common.
In order to optimally join both disease fields, two international networks will join their expertise and efforts in this study: the pan-European research group on detection and timely INTERvention in DEMentia (Interdem) and the European Association of Palliative Care (EAPC).

Abstract number: P330
Abstract type: Poster

Implementation of Improvement Strategies in Palliative Care: An Integrative Review

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Introduction: It is difficult for health care professionals in palliative care to keep up with the rapid advancements in evidence based medicine. Finding better ways of implementing best practice in this field is therefore of utmost importance, especially since the European population is aging and an increasing number of people are in need of palliative care. The aim of this review is to provide an overview of implementation strategies that are currently used to improve the organisation of palliative care for patients with cancer and dementia care settings as part of the EU funded IMPACT project (IMPAlliative Care sTudy).

Abstract number: P331
Abstract type: Poster

Blood-based Gene Expression Profiling for the Diagnosis and Early Detection of Lung Cancer

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Aims: Lung cancer (LC) is the leading cause of cancer-related death worldwide. This project aims to explore the applicability of blood-based gene expression (GE) profiling for the detection of early stage LC.

Methods: GE profiling was performed on samples from 137 LC patients included in the Central Norway Lung Cancer Biobank (CNLCB), 155 cancer-free controls selected among participants in the North-Trøndelag Health survey (HUNT 3 study), and on 68 samples (34 duplicates) of cancer-free females from the Norwegian Women and Cancer Study (NOWAC). Cases and controls were matched on age, sex, and smoking history. Blood was sampled on RNA-stabilizing tubes from PAXgene® and Tempus™, and GE profiling was performed using the Illumina Human-6-v2 Expression Beadchip. GE analyses will be carried out using the Illumina BeadStudio software.

Results: RNA isolation, quality control and gene expression profiling have been completed. An extensive statistical analysis is currently being carried out to extract genes consistently differentially expressed between patients and controls. The GE profiles will also be stratified by histological subtypes and analyzed for any correlation to treatment response and survival time. Final results will be presented at the conference.
**Conclusion:** We expect to identify a set of genes that are differentially expressed between LC patients and cancer-free controls, and that can be further developed and used as a supplementary tool for the diagnosis and early detection of LC. We also hypothesize that added diagnostic and prognostic value can be obtained by combining the blood-based GE profile with the corresponding GE profile from the tumor.

**Source of funding:** The study was financially supported by The Norwegian Research Council through the FUGE 2 program.

**Abstract number:** P332
**Abstract type:** Poster

**A Holistic Exercise Rehabilitation Programme for Patients with Cancer Related Fatigue - A Pilot Programme of Translational Research**

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**Background:** The number of people living with and beyond cancer is increasing, but due to the after effects of disease and treatments many individuals who have survived cancer do not enjoy the same quality of life as the general population. The aftercare provision for this population is largely biomedical in orientation, focusing on monitoring and surveillance of recurrence. Research indicates the importance of well-being and the use of exercise rehabilitation in the management of CRF.

**Objectives:** The Back on Track (BoT) 8 week pilot service was designed to evaluate an individually tailored exercise rehabilitation programme based on the evidence gathered from multiple randomized controlled trials into the use of rehabilitation interventions for CRF.

**Method:** Individuals who had completed curative cancer treatment were recruited from the Ulster Cancer Foundation. A holistic baseline assessment of the 18 participants was carried out at the University of Ulster. Following this, a personalised 8 week exercise programme was agreed with each participant. 12 participants chose a home based aerobic and resistance training programme with weekly telephone support and 6 chose to attend a weekly exercise programme at the University along with home based aerobic and resistance training. On completion of the programme the outcome measures assessed at baseline were repeated. 17 of 18 participants completed the baseline and follow up assessments.

**Results:** Significant improvements following the intervention were noted in the 6 minute Walk Test, the Fatigue VAS, the FACT- F, the Beck Depression Inventory, the BORG scale post 6 MWT, Triceps skin-fold thickness and timed sit to stand. These improvements were achieved with both intervention programmes.

**Conclusion:** An eight week home-based exercise rehabilitation programme with or without weekly gym based activity appears to make significant improvements to both physical and psychosocial outcomes in patients with CRF.

**Abstract number:** P333
**Abstract type:** Poster

**Conversations for Life: Implementation of a Pilot Public Awareness Campaign about End of Life Issues**

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**Background and aim:** Greater public awareness about end of life issues is identified as a priority in English national policy. An integrated public health campaign was designed and piloted in one English county. It aimed: To improve awareness about, and increase, advance care conversations amongst the general population.

**Methods:** Personal stories are at the core of this campaign as they are a powerful tool for communication around sensitive issues such as end of life care. The public awareness campaign comprised three elements: 1. A DVD showing stories by local people of their personal experiences; 2. Development of materials (web and print), signposting information and resources; 3. Facilitated workshops about end of life conversations and care. An evaluation of each workshop was undertaken using a short survey form and analysed using descriptive statistics and a coding of responses to open questions.

**Results:** The DVD “Breaking the Silence” was made using the narratives of 8 local people with a range of experiences of living with life threatening conditions and/or caring for people who were dying. There have been 17,771 visitors to date (averaging 22.6/day) to the website. 93 people attended 11 workshops in 6 locations across the region. The evaluation response rate was 89%. 84 % of respondents had learnt how to hold end of life conversations, make choices, access resources and could begin to make their own future plans. 98% of participants would recommend the workshop to others. Answers to the open questions showed this new knowledge was important for people as they started planning and communicating with family members.

**Conclusion:** This pilot has demonstrated that a community-based public awareness campaign on end-of-life issues can reach the public and achieve greater awareness/educational outcomes. The trademarked campaign is being introduced regionally and (inter)nationally under a not-for-profit social enterprise.
The Benefits Perceived by Students Taking a Foundation Degree of Seeking Patient Feedback as a Formative Part of Education

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**Aims:** To explore the benefits students taking a foundation degree in palliative and supportive care perceive in seeking formal feedback from patients and families as part of their education.

**Methods:** Twelve students taking a two year foundation degree in palliative and supportive care were interviewed in groups at three time points. Transcribed interviews were analyzed thematically by two researchers.

**Results:** Students enjoyed receiving feedback, commenting that positive feedback helped increase confidence, reassure and ‘spur them on’. They felt that negative feedback could also be beneficial, allowing them to look critically at their practice and pick up areas of weakness they may have been unaware of. They were unsure as to whether there was any other such mechanism currently available for looking at this. Many of the students had worked in their current jobs for a considerable length of time and had never received any feedback on their performance. Culturally they felt feedback has been reserved for when things have gone wrong, with people quick to complain and criticise and less likely to comment on positive elements. In what they perceive as an environment where there is much negativity from patients and families, feedback helped increase morale.

**Conclusions:** Patient and family feedback is considered a key formative educational strategy and is a requirement for clinical training of doctors. Its use in nurse and other health and social care worker training is not established. The experience of students in this foundation degree demonstrates some key educational and development benefits to this as an educational strategy.

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**Aims:** While researching the evidence regarding various methods of delivering core competencies in Palliative Care to postgraduate medical learners, the authors discovered that there is little evidence for block rotations for learners, as a key teaching method. Rather, evidence suggest that multi modal strategies need to be implemented and woven into the clinical teaching curriculum. This runs contrary to current standard teaching. We have developed a customized menu of offerings that are tied to specific competencies from which the learner can self select and self monitor completion. This menu of competency based offerings will be detailed during this session.

**Methods:** This presentation will demonstrate how we arrived at this multi-faceted, competency driven method of teaching postgraduate learners the essential palliative care competencies, and how such a complex menu of offering is organized and delivered across several campuses and programs.

**Results:** This innovation is interesting as it takes the evidence from the educational literature and via implementation of that evidence, completely shifts our focus of teaching. As many if not most schools also rely on a certain block clinical rotation in palliative care, as the “backbone” of their palliative care curricula, this innovation shows us how to move away from a comfortable but pedagogically unsound program to one that is rich in options and pedagogically sound.

**Conclusion:** Curricula leaders in Palliative Care, will need to learn how shift away from traditional palliative care teaching to methods and strategies that are evidence based and pedagogically sound.

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**Aims:** The aim of this project was to evaluate whether e-ELCA could provide time- and cost-effective end-of-life education in a difficult economic climate, engage staff in a novel way of continuing professional development, and make workforce development in end-of-life care ‘real’.

**Abstract number:** P335
**Abstract type:** Poster

**Integrating Palliative Care into Postgraduate Curriculums - A Surprising but Evidence Based Approach**

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**Methods:** Teaching postgraduate learners the essential palliative care competencies, and how such a complex menu of offerings will be detailed during this session.

**Results:** The implementation of that evidence, completely shifts our focus of teaching. As many if not most schools also rely on a certain block clinical rotation in palliative care, as the “backbone” of their palliative care curricula, this innovation shows us how to move away from a comfortable but pedagogically unsound program to one that is rich in options and pedagogically sound.

**Conclusion:** Curricula leaders in Palliative Care, will need to learn how shift away from traditional palliative care teaching to methods and strategies that are evidence based and pedagogically sound.

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**Abstract number:** P336
**Abstract type:** Poster

**e-ELCA: An Innovation in Improving End-of-Life Care**

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**Background:** In large healthcare institutions and in the wider community setting, effective education of all staff who care for patients towards the end of their lives can be difficult to achieve. The End of life care of all (e-ELCA) is a free e-learning package designed to increase learners’ knowledge about end of life care that blends and complements existing educational programmes. It is aimed at all health and social care staff who have contact with those requiring end of life care in order for them to have the necessary skills to care for such patients.

**Aims:** The aim of this project was to evaluate whether e-ELCA could provide time- and cost-effective end-of-life education in a difficult economic climate, engage staff in a novel way of continuing professional development, and make workforce development in end-of-life care ‘real’.

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**Abstract number:** P337
**Abstract type:** Poster

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**Methods:** Twelve students taking a two year foundation degree in palliative and supportive care were interviewed in groups at three time points. Transcribed interviews were analyzed thematically by two researchers.

**Results:** Students enjoyed receiving feedback, commenting that positive feedback helped increase confidence, reassure and ‘spur them on’. They felt that negative feedback could also be beneficial, allowing them to look critically at their practice and pick up areas of weakness they may have been unaware of. They were unsure as to whether there was any other such mechanism currently available for looking at this. Many of the students had worked in their current jobs for a considerable length of time and had never received any feedback on their performance. Culturally they felt feedback has been reserved for when things have gone wrong, with people quick to complain and criticise and less likely to comment on positive elements. In what they perceive as an environment where there is much negativity from patients and families, feedback helped increase morale.

**Conclusions:** Patient and family feedback is considered a key formative educational strategy and is a requirement for clinical training of doctors. Its use in nurse and other health and social care worker training is not established. The experience of students in this foundation degree demonstrates some key educational and development benefits to this as an educational strategy.
**Method:** The project team recruited 26 members of staff (nurses, allied health professionals and healthcare support workers), to take part in the pilot. Each participant chose one module from the programme to progress as far as they could over an 8-week period. A pre-pilot workshop was held to enable participants to ‘have a go’ within a supportive environment. Participants received support from their managers and were also able to apply for remote computer access enabling them to study at home using e-ELCA if they wished.

**Results:** 94% of participants stated they would recommend e-ELCA to others and 47% stated they would definitely continue further study. Participants completed the module in a variety of ways, alone, in combination with a partner or as part of a group. Only 25% were allocated study time to complete the module.

**Conclusion:** e-ELCA appears to be an effective way to engage with staff in providing training in end-of-life care, however a majority of participants identified lack of time as a significant difficulty and limitation of the e-ELCA.

**Abstract number:** P337
**Abstract type:** Poster

**Educational Visits to a Hospital Palliative Care for High School Students**

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In this moment, Palliative Care (PC) is emerging in educational programs. There are numerous references on training medical students. There are Universities that give the opportunity to visit hospice but no references found about the experiences with high school students.

**Aim:** To develop educational visits (EV) to a palliative care hospital by high school (HS) students and know the impact on the students.

**Methods:** Our centre is a 43-bed PC hospital. Usually many HS Centers visit us and all of them accepted to participate in this study.

The EV consists on visiting the hospital’s facilities during 45 minutes and a talk about PC during others 45 minutes.

At the end, students fill an anonymous survey to collect opinions on improvements in their knowledge, perception of priorities and usefulness of training. All of them consent to the verbal authorization to be used.

The study was developed from January to June 2011.

**Results:** A total of 7 HS Centers with 159 students visit our hospital. Some 148 responders were female. Median age was 25 years (range: 14–58). For 98% is their first visit to a hospice. The 89% think that EV, agreed strongly as a positive experience, 93% think facilities are adequate, 92% say it helps them in their future professional training and 99% recommended EV to another students. The topics learned about PC are cares 35%, treatments 20%, managements 13%, the difference between sedation and euthanasia, and attitude and aptitude of the professionals, 11%.

**Conclusions:** High Education students value positively these EV. They require learn aspects of treatment and comprehensive care to patients.

We suggest further comparative studies in other Hospices and increase the number of students. More qualitative studies to know students opinion and their reasons, is suggest too.

We would recommend this specific EV in palliative care to be improved the educational knowledge to the end of life.

**Abstract number:** P338
**Abstract type:** Poster

**Paying Attention to Death and Dying in Medical Education: A Narrative Inquiry of Junior Doctors’ Personal Experiences of Death and Dying**

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Studies show that death and dying are a source of distress for junior doctors that can affect their patient care, negatively influence job satisfaction and adversely affect their personal lives. This doctoral research aims to explore junior doctors’ experiences of death and dying, asking to what extent medical education and the culture of medicine prepare and support doctors for this work.

Narrative inquiry research explores personal experience to create new meanings and consider different ways of seeing the world. I use this method to study doctors’ experiences of death and dying as experience is central to how doctors learn. As a palliative medicine doctor-educator, I have interviewed twelve junior doctors about their memories of death and dying. In the interpretation and analysis of my data I have used a holistic, multifaceted approach that makes links between personal, social and cultural dimensions. I have examined the medical context of death and dying, reviewed relevant medical literature and analysed national guidance for medical education. Using writing as a method of inquiry, I have also re-presented the doctors’ narratives as fictional stories giving them a voice that they felt was lacking both in their training and place of work.

This research shows that medical education marginalises death and dying. Experiences of death are also significant for doctors. Some find ways to integrate these into their lives that positively contribute to their emerging
identities. Most feel unprepared for death and describe a workplace culture where death is a clinical event, doctors learn to hide their emotions and ‘get on with the job’.

I argue that the medical profession should pay closer attention to how it educates and supports students and junior doctors about death and dying. They might then learn to ‘know’ about and feel more at ease with this so as to develop their skills to care for the dying and find personal meaning from these unavoidable encounters at work.

Abstract number: P339
Abstract type: Poster
Madrid Program for All Primare Care Professionals: Information and Training Delivered in Health Centres

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Background: Palliative Care (PC) is a human right: must be accessible to all who need it. There is evidence that training professionals in all settings improve patient’s quality of care.

Objectives: To promote professional sensibility and improve knowledge in identifying, caring for and treating patients with advanced illnesses in order to enhance their and their families’ quality of life. To agree a needs plan for each health centre. To exchange information between Primary and Palliative Care professionals sharing patient care.

Methods: Participative 4 hours training sessions were offered to all 261 Primary Care Health Centres by the Regional PC Coordinator. We sent a letter to the Primary Care Zone Education Leader and Health Centre Coordinator explaining the program and asking them to encourage staff attendance. The sessions were offered in the best possible slots for attendees. During each of the sessions, the topics addressed were:
- Basic Concepts.
- Regional PC Strategy.
- Needs centered PC (Levels of complexity and intervention).
- Regional and local PC coordination.
- Referral criteria.
- PC teams availability.
- Team working.
- Specific needs identification.

Results: Seven sessions were organized and delivered in each of our seven zones total attendance of about 350 professionals. Representatives from all local PC teams were also invited with over 40 PC teams being involved. Altogether close to 1000 professionals (Primary Care and PC professionals) were involved in the program.

Conclusions: The program has helped to extend PC culture, information exchange and identify needs and improvements as summarized in three documents drawn:
1. Incorporates attendees ideas, concerns and proposals.
2. Incorporates training team’s observations;
3. Combines these results with those obtained from the same program delivered to the region new 11 hospitals 12 months before.

Abstract number: P340
Abstract type: Poster
Focussed Ultrasound Training for Palliative Care Clinicians

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Background: The use of limited ultrasound assessments by individual physicians to aid clinical decision making has become normal practice in a range of medical and surgical specialties, particularly when access to a full ultrasound service is not readily available or would necessitate transferring particularly vulnerable patients. Focused Abdominal Ultrasound in Palliative Care (FASP) training aims to teach palliative clinicians how to make use of Ultrasound within their own personal clinical practice to improve patient safety and comfort.

Methodology: The FASP programme was first run in 2008 and since then has been held at four centres across the UK over the course of a weekend. As part of the governance process of FASP, candidates have the opportunity to record anonymous details of the scans performed in the various clinical scenarios which FASP teaches. For four months following training at the Princess Alice Hospice, with candidates permission the scans logged were analysed.

Results: 30 entries were recorded during this time by six course candidates, from the 16 who attended the course.
- Six entries had insufficient data and were excluded.
- 20 patients had 24 scans carried out.
- Of the 13 occasions when ascites was suspected, the ultrasound scan confirmed this ten times, avoiding three unnecessary paracenteses.
- Six patients had ultrasound scans to check if there was a distended bladder, which was confirmed in three patients.
- Transfers to hospital for scans to check for ascites were reported as being avoided on three occasions.
One jaundiced patient had dilated bile ducts on the scan, which helped the decision to transfer to hospital for further investigations.

Physicians reported they had found the scan helpful in 88% (21/24) of entries.

**Conclusions:** The FASP course can equip palliative care clinicians to make use of Ultrasound technology to help in particular clinical decisions when access to a full Ultrasound service is not readily available.

**Abstract number:** P341
**Abstract type:** Poster

**Evaluation of an End of Life Care Link Nurse Initiative for Residential Care Settings in the Republic of Ireland**

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**Aim:** During 2010-11, five hospice education centres developed and implemented a collaborative, standardised end of life care link and associate nurse initiative for residential care settings for older people in their catchment areas. Registered Nurses (n=107) from participating residential care settings for older people (n=41) attended a five day end of life care education programme, which was facilitated by their local hospice education centre. The programme aimed to prepare the Registered Nurses for the role of End of Life Care Link or Associate Nurse, so that they could deliver a blended learning end of life care education programme to their nursing and health care assistant colleagues in their workplace. To assist them establish and sustain their roles, resources were identified and developed including an on-line facilitator and a support forum provided by each hospice.

**Methods:** End of Life Care Link and Associate Nurses completed a pre-course worksheet (n=94, 88%), a post-course worksheet (n=98, 92%) and a course evaluation form (n=90, 84%). Hospice educators (n=7) and specialist palliative care professionals (n=8) completed an evaluation form regarding their experiences of facilitating the five day programme. In the winter of 2011, telephone interviews will be conducted with stakeholders and in the spring of 2012, each hospice will facilitate a focus group with the End of Life Care Link and Associate Nurses to explore their views of the initiative.

**Findings:** Data collected and analysed to date, suggests that the education initiative has been a positive learning and teaching experience, but the education materials need to focus more on palliative and end of life care issues for non-cancer residents. Data collection and analysis will be completed by March 2012. The initiative is supported by the Irish Hospice Foundation.

**Abstract number:** P342
**Abstract type:** Poster

**What Impact Does High Fidelity Simulation Have on Nurses’ Confidence and their Perceptions of their Knowledge and Skills in End of Life Care?**

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**Aims:** To explore the impact of teaching end of life care to band 5 and 6 nurses using high fidelity simulation. This study looked at the impact of high fidelity simulation on the nurses’ confidence and their perception of their knowledge and skills in end of life care.

Palliative care education has become a priority. The need for good quality end of life care to be delivered to all dying patients is paramount. With over half the population dying in the acute setting, all hospital staff should be trained in providing good quality end of life care. Although medical simulation is a relatively new teaching modality, it does enables experiential learning.

**Methods:** There were a total of seven participants from two separate cohorts. All participants were asked to complete a pre and post course questionnaire. Additionally, pre and post course focus groups were conducted which were videotaped and transcribed verbatim. Emerging themes were identified through thematic analysis in both the pre and post course data.

**Results:** The study demonstrated that there was a significant impact on confidence, knowledge and skills for participants’ of this end of life course. The participants gained confidence and knowledge in a number of aspects of end of life care and described learning new skills surrounding communication. High fidelity simulation allowed participants’ to reflect on their own practice and trial new approaches in a safe but realistic situation. The facilitated debrief session’s encouraged self reflection, constructive feedback and the opportunity to reflect on others clinical practice.

**Conclusion:** Although this study does highlight the significant participant benefits of using high fidelity simulation to learn it must be remembered that there are other teaching modalities available. Future research
should look at the impact of using high fidelity simulation compared to another teaching modality in teaching end of life care.

Abstract number: P343
Abstract type: Poster

Towards a Comprehensive Educational Framework for Palliative Care: The Development of Competency Models for Disciplines Involved in Palliative Care

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Background: A firm educational framework is essential for the advancement and provision of palliative care within a healthcare system (Smiedig & Larsson, 2001). However, despite the indisputable logic of this statement, palliative care is not acknowledged as a distinct educational topic within healthcare curricula in the Netherlands (Groot et al., 2009).

Aim: In order to fill this gap, we set out to develop a comprehensive educational framework for palliative care. To meet the standards of current medical education frameworks which will aid implementation after our project is finalized, our goal was to identify competency models. These competency models will in turn provide the framework for the development of Competency Based Training Programs, a type of educational program that has spread rapidly to better fit the changing demands of our healthcare system (ten Cate, 2006).

Method: A two step study protocol was designed:
(1) identify all disciplines involved in palliative care; and
(2) construct a Critical Incident Survey to establish the competencies needed by each of these disciplines to provide good quality palliative care.

Results: A total of 27 associations agreed to participate, ranging from surgical oncologists to dietitians. Also, a Critical Incident Survey was designed that will enable us to establish the competency models of all participating professional groups, and, in a subsequent phase, competency based curricula to formally educate for palliative care. The survey study will be conducted December 2011. Preliminary results will be available for presentation at the conference.

Conclusions: We expect this study will provide the vital basis needed for the development of educational frameworks and curricula that will give palliative care its rightful place in healthcare education.

Abstract number: P344
Abstract type: Poster

Testing a Complex Intervention for the Improvement of Cancer Pain Control in Hospital

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Primary objective: To improve the cancer pain control in patients admitted to medical wards of the regions concerned, experiencing a complex intervention programme (information to patients, personnel training, organizational support) called PACIFICO.

Model: Phase II pre-post quasi-experimental study - multicentric.

Inclusion criteria: At ward level: Medicine, Oncology and Pneumology hospital departments of five Italian regions; at operators’ level: physicians and nurses working in the selected departments.

Methodology: The training takes place at two levels: guides and teams. The guides, after being formed, will “contaminate” their colleagues. Their education aims at acquiring knowledge related to pain control, conducting peer training events, reproducing a specific educational content, discussing clinical cases and developing peer to peer counselling. It’s a package consisting of 14 lecture hours, followed by a 8 hours distance education and a final 6 hours module. An educational kit is provided. Inside their departments, the guides will then reproduce an educational event lasting 12 hs., discuss 3 clinical cases, have at least one peer to peer interview with each health operator and predispose the final audit (team level).

Instruments: APS-POQ and PAK ScaleResults. 6 departments recruited, 12 guides completed their educational path and are now managing the field training. It’s now in progress the second phase of the trial, which includes the spread at team level.

Conclusions: The study is in progress. The final results will be available in May 2012. The expected transformation can be traced back at patient: regular information about pain treatment to all inpatients; regular use of a NRS scale and subsequent correct therapeutic prescription and administration; pain relief in hospitalized patients. At operator level: improved knowledge and skills regarding pain management. Study financed by the Italian Health Ministry.
Aims: Unregistered health and social care workers arguably provide the bulk of end of life care. The Foundation Degree in Palliative and Supportive Care (FD) is an educational initiative specifically developed for health and social care support workers. The FD hopes to influence the quality of palliative, supportive and end of life care provided for patients in all care sectors. The evaluation of the FD began in 2008 and continues until 2013, following the students for three years after completion of the FD. The evaluation will assess the impact of the FD for patients and relatives; students; colleagues and employers. This paper looks only at the outcomes for students related to career and role changes to date.

Methods: The study uses both quantitative and qualitative methods. Interviews, focus groups and questionnaires with 10 support workers undertaking the FD were carried out at several time points over the two years of the FD and subsequently. Support workers not undertaking the FD also completed questionnaires.

Results: Many students hoped that the FD would improve their future career prospects, lead to promotion or a specialist post and a higher level of pay. These were motivating factors throughout the duration of study. Six students completed the FD: 2 suspended their studies due to personal circumstances and 2 dropped out of the course. One year after the FD 2 students had changed jobs. One because of a key career opportunity and one because of dissatisfaction with the palliative care and their role in influencing this in their place of work. Four other students had changed roles within their place of work to include a greater remit in palliative care. Four students had gone on to further study one year after completion of the FD.

Conclusions: The 60% completion rate highlights the challenges in undertaking study at this level. The FD facilitated career change and further study. Role change without pay or grade change was usual. Some had no role change.

Abstract number: P346
Abstract type: Poster

Palliative Care through Telemedicine. A New Friendship?

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Aims: Acquire communication skills by Health Professionals who are involved in the management of patients and families at the end of life. Promote the use of telemedicine for the delivery of specialist support at home. Observe the effectiveness of teleconsultation in complex palliative homecare.

Methods: To extend communication skills and palliative care tools outreach to remote areas, a digital videoconferencing link was established between five Primary Healthcare centers and a Palliative Care Support Team located in Perpetuo Socorro Hospital In Badajoz, Extremadura in the west of Spain.

Primary Care Professionals have a weekly teleconsultation with a nurse and a physician of the palliative consultation team. They teach about communication skills in an hour session. After the talk, there is a discussion about case patients and they advise Primary Care Professionals on treatment policy of the patient.

An evaluation tool is developed for professionals and they send them by post.

Results: Problems already encountered are small professional numbers at any one time who utilize the resource to improve their communication abilities or Palliative Care Skills.

Approximately, 35% of Primary Care Professionals use this way to acquire new tools in Palliative Care. About 90% of participants respond the test. The majority of them consider very useful Telemedicine as a new tool to improve Palliative Care skills as a good way to make contact with an expertise Palliative Care Team.

Conclusion: Telemedicine is an innovative approach to develop Palliative Care skills and to deliver quality of care for palliative patients at home.

Abstract number: P347
Abstract type: Poster

20 Years of Undergraduate Education in the Palliative Medicine Chair and Department at Poznan University of Medical Sciences

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Palliative Care (PC) courses for undergraduate students of medicine at the Poznan University of Medical Sciences was first introduced in 1991. Subsequently, the undergraduate courses for nursing students and in the recent years- for the physiotherapists and premedics were introduced (20-25 hour programmes). At present, a total of c.1800 students, including a group of 200 foreign undergraduates
(mostly from Norway, the USA and Taiwan), attend the courses. The 54-hour programme for medical students includes the introduction to PC, pain and other symptoms palliation, the chronic wounds management, psychological reactions to the life-limiting diseases, patient and family support, clinical communication skills and ethical issues in PC. Seminars and workshops are supplemented with the teaching at the bedside on the in-patient unit and in the outpatient palliative care clinic at the Poznan Hospice. The evaluation forms filled by each student at the end of the course is helpful in reaching the goals of the training and generates a better response to the students’ expectations. The feedback clearly shows that bedside teaching, as well as learning of practical aspects of pain treatment (analgesics, dose adjustment, monitoring of the treatment etc.), and communication skills, are considered the most important by the attendees. It is worth mentioning that, in addition to undergraduates, as many as c.90 postgraduate physicians and nurses attend each year the 1-4-week training in Poznan PC Chair and Department, as a part of the postgraduate and specialization education (including 2-6 people from Eastern European countries, in cooperation with Eastern and Central Europe Palliative Care Task Force, ECEPT). The 20 years of experience resulted in consolidation of the multi-professional teaching team including physicians, specialist nurses, physiotherapists and psychologists.

**Abstract number:** P348  
**Abstract type:** Poster  

**End-of-Life Care and People with Intellectual Disabilities: Service User and Professional Perspectives**  

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This study aimed to explore service user and professional perspectives in end-of-life care for people with intellectual disabilities and to establish examples of good practice to enhance care. Concerns exist regarding the quality of end-of-life care for people with intellectual disabilities, who are living longer leading to the risk of advanced disease.

A sequential, exploratory mixed methods research design was used. In Phase 1 qualitative data were obtained from semi-structured interviews with a purposive sample of interdisciplinary professionals (n=30) and family carers (n=5), and from two focus groups with people with intellectual disabilities (n=17). This data informed Phase 2- a quantitative, regional scoping study of end-of-life care provision to people with intellectual disability, using a total sample of intellectual disability and specialist palliative care services (n=66) which generated a 71.2% (n=47) response rate. Qualitative data were subjected to thematic analysis and quantitative data were analysed using descriptive statistics as frequencies and percentages. Findings of Phase 2 confirmed those of Phase 1 and both integrated data sets identified a range of professional learning needs and service improvement issues across services, which reflect those within the National Gold Standards Framework for End-of-Life Care. The findings also suggest that joint working and learning between intellectual disability and palliative care services could help to address these issues evidenced through examples of good practice which emerged from the study. Benefits, enablers and challenges to joint service working have also been explored.

This study has provided greater awareness of learning needs and service improvement issues in this area of practice and the role of collaboration in addressing these needs. The findings may have international significance for further exploration of joint working and learning between other specialties in end-of-life care.

**Abstract number:** P349  
**Abstract type:** Poster  

**The Perspective of Nurses about Critical Success Factors in the Primary Process of Palliative Care**  

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**Aim:** The purpose of this study is to explore the critical success factors, as the principal sum of barriers and facilitators, within palliative care from the perspective of nurses.

**Methods:** This exploratory, descriptive study involved a developmental design. First, six focus groups were conducted at six geographical locations with nurses working within different palliative care settings. Participant responses were transcribed and entered into MAXQDA10 software for data management and coding. Subsequently a new structured questionnaire was developed based on the themes describing the ideal situation. For each item within the themes nurses can determine whether this is a problem in daily practice and which priority has to be solved. Finally, this questionnaire will be conducted in December 2011 with all 34.000 members of V&VN, the Dutch Nurses’ Association.

Conclusion: In this first study relating the ideal palliative care situation of nurses, they describe this situation in eleven themes. After analyzing the second part of this study conclusions will be made, which can make a difference in the discussion about development of palliative care in the Netherlands in daily practice as well as in policy.

Abstract number: P351
Abstract type: Poster

The Pattern of Antimicrobial Use for Palliative Care In-patients during the Last Week of Life

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Background: In terminally-ill cancer patients approaching the dying phase, liberal use of antimicrobials is often viewed by palliative care experts as irrational. No previous reports have reviewed current antimicrobial use in palliative care settings in Saudi Arabia.

Objective: The objective of this study was to explore the pattern of antimicrobial use in a tertiary palliative care unit (TPCU) during the last week of patients’ life.

Methods: Medical records of all patients who died in the TPCU over a 14 month period were reviewed for demographics as well as the frequency and rationale of antimicrobial use during the patients’ last week of life. Information on antimicrobial use was obtained from a computerized pharmacy database.

Results: Of 138 patients who died with advanced cancer in the TPCU, 87 (63%) were on one or more antimicrobials during their last week of life. Antibiotics were more frequently used as compared to antifungal and antiviral agents, 64 (46.4%); 45 (32.6%); and 2 (1.5%), respectively. About one third (31.3%) of patients who received antibiotics during their last week of life were prescribed more than one antibiotic. Antimicrobials were mostly given systemically (79%) rather than topically (21%). The most common rationales for antimicrobial prescribing were oral thrush in 36 patients (25.4%), wound care in 29 patients (20.4%), and on empirical basis in 29 patients (20.4%).

Conclusions: The current practice of antimicrobial prescribing, especially for patients who are eminently dying may need to be reviewed. Initiation of antimicrobial treatment in this group of patients should be based on clear treatment goals and desired outcomes, considering views of patients and families.

Abstract number: P352
Abstract type: Poster

Intervention to Improve Care at Life’s End in VA Medical Centers

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Aims: The primary aim of this study was to evaluate the effectiveness of an educational intervention to improve processes of end-of-life care in VA Medical Centers (VAMC).

Methods: The BEACON trial (Best Practices for End-of-Life Care for Our Nation’s Veterans) was a multi-center, pre-post intervention trial, in six VAMCs. Introduction of the intervention at each medical center was staggered across time at six-month intervals using a multiple baseline design. The multi-modal intervention was targeted broadly to hospital providers, including physician, nursing, and ancillary staff. The purpose was to train hospital staff to identify patients who were actively dying and to implement the best practices of traditionally home-based hospice care in the inpatient setting. Staff training was supported with written materials, a Comfort Care electronic order set for dying patients, and follow-up consultation. Data on processes of care in the last seven days of life were abstracted from the computerized medical records of veterans who died in the six VAMCs 12 months before intervention (n=1,079) and 12 months after intervention (n=1,130).

Results: The proportion of patients with an order for opioid pain medication at the time of death increased from 66.0% to 70.4% (p=.02) and the proportion with a do-not-resuscitate order in place at time of death increased from 69.2% to 74.1% (p=.04). Changes were not statistically significant for the proportion who died in the intensive care unit (41.2% to 37.7%, p=.21), proportion with a nasogastric tube or intravenous line at time of death (38.0% to 35.8%, p=.18) or proportion who were in restraints at or near time of death (16.2% to 16.7%, p=.74).

Conclusions: This broadly targeted intervention to change practice patterns for end-of-life care led to modest but statistically significant changes in some processes of care. Further research is needed to identify optimal methods to improve quality of end-of-life care in acute care settings.
Aim: The patient’s quality of life, a concept which relies very much on personal experience, is an important factor in end-of-life decision-making. That is why in palliative care patients’ preferences about receiving or withdrawing possible medical treatments are valued highly. Therefore we studied the public’s preferences on (non)treatment decisions. Besides that we look at differences between the public and people with an Advance Directives (ADs), because these documents are a mean to make one’s preferences known.

Methods: As research population a representative sample of the Dutch population (n=1402, in general not owning ADs) and a cohort of people who own an AD were used. The cohort was recruited through two associations, who give out standard ADs in the Netherlands, the NVVE (Right to Die-NL, n=4575), which provides a do not resuscitate order and a refusal of treatment document, and the Christian orientated NPV (n=1261) which provides a will-to-live statement. All the participants answered written questionnaires in 2005 or 2007. For this study, we used two hypothetical scenarios, one in which they would be in an advanced stage of cancer and the other in an advanced stage of dementia, and asked questions about certain medical treatments showed similar results.

Results: To the question if they wanted to be resuscitated 97% of the NVVE-members answered (probably) not in case of advanced cancer and 99% in case of advanced dementia; the NPV-members answered (probably) not in 53% (cancer) and 47% (dementia), the general public in 86% (cancer) and 86% (dementia). Questions about other treatments showed similar results.

Conclusion: The results show that the preferences from NVVE-members have a strong tendency towards forgoing treatment, which concurs with their ADs. The preferences of the general public follow this tendency, however not as explicit. The preferences from the NPV-members are scattered, while they all own the same AD, and differ significantly from the other two groups.
Research aims: Information on psychological and social burden of terminally-ill patients in different care settings, independent of the type of disease, is scarce. The aim of the study was to assess the psychological and social burden at the end of life in Germany. We further wanted to investigate differences in the perceived burden for various places of death.

Study design and methods: The cross-sectional survey was based on a random sample of 5000 inhabitants of Rhineland-Palatinate that had died between 25 May and 24 August 2008. Relatives of these randomly drawn deceased persons were interviewed by means of a written survey. In bivariate analyses, we determined whether patients dying in different places had different patterns of psychological and social burden.

Results: People most frequently suffered from moderate to severe anxiety (62.5%), followed by tension (60.1%), confusion/disorientation (55.4%), and depressiveness (45.8%). Concerning the social burden, almost all proxies stated that their deceased relative needed moderate to severe help in daily activities (87.9%). Comparatively less people mentioned a moderate to severe overburden of family (39.0%) or problems with organization of care (32.9%). There were significant associations between place of death and psychological and social burden: Tension (emotional strain) was most frequent in hospitals, confusion/disorientation in nursing homes. Need for help in daily activities and overburden of family were highest at home.

Conclusions: Our investigation reveals evidence for a high psychological and social burden of the dying in different places of death. These results thus emphasize the necessity for psychological and social support of dying patients and their relatives in all places of care and regardless of the type of disease.

Abstract number: P356
Abstract type: Poster

Falling in the Context of Advanced Cancer; The Tension between Preserving Self-identity and the Physical Self

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Aims: Research has shown that 50% of adults with advanced cancer experience a fall during follow-up of up to 6 months. The impact of falling within the context of having advanced cancer is unknown. The aims of this study were to explore the impact of falling in patients with advanced cancer, in order to inform the development of falls prevention strategies in this population.

Methods: Classic Grounded Theory methods of data collection and analysis were employed, using qualitative data. Unstructured interviews were conducted with adults with advanced cancer in receipt of palliative care services who had experienced a recent fall. Field notes were also collected from informal interviews with participants of a quantitative study of falls risk factors. Transcripts/field notes were coded using constant comparison of incidents to generate categories and memos and purposive sampling to facilitate saturation of core and related categories. Sorting of theoretical memos generated an integrated theory encompassing the relationships between concepts.

Results: 14 formal & 5 informal interviews were conducted. Preserving self; Self-identity (Articulating identity, Avoiding de-personalisation) and Physical self (Rationalising risks, Physical vigilance) was the core activity of participants. The tension between the 2 dimensions of Preserving self also determined extent of analysis of personal factors in causing a fall and adoption of falls prevention strategies.

Conclusions: In the context of advanced cancer, falls may precipitate transitioning. Strategies to reduce and manage falls must compliment patient defined self-identity.

Abstract number: P357
Abstract type: Poster

Refusal of Care at the End of Life

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Background: Although anticipated by law, refusal of care from competent patient at end of life raises questions in the relationship with health professionals, thus creating tension.

Objective: The main objective of this research was to study nurses’ representations and attitudes regarding refusal of care from dying patients in order to provide benchmarks for a clinical approach.

Methods: We conducted a qualitative study with 12 interviews recorded and fully transcribed. Discourse analysis was done manually and with software Alceste.

Results: Health professionals are willing to respect the refusal of care, particularly at end of life, without always seeking for a meaning. Their representations, their projections, their feelings lead to some specific attitudes. For nine nurses, defensive coping strategies were used, with for the majority, some avoidance behavior (not listening,
trivialization, avoidance), but also negotiation. Only three nurses adopt an open-mind and questioning attitude.

**Conclusion:** This research should lead us to be more aware about the meaning of the refusal of care, beneficence, respect for autonomy, its limits and underlying conflicts of values. Only a relationship, involving all the multidisciplinary team in a clinical approach focusing on communication, trust, patience, promotes the emergence and respect of patient autonomy.

**Abstract number:** P358  
**Abstract type:** Poster  
**Organ and Tissue Donation on a Tertiary Palliative Care Unit - How Common Is this Practice?**  
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**Aims:** Our Tertiary Palliative Care Unit (TPCU) admits patients identified by palliative care consultants as having problematic symptom and psychosocial issues difficult to manage in other care locations. A change in provincial legislation has placed an emphasis on the physician to determine patient organ and tissue donor status. The intent of the legislation is to ensure that a patient’s wishes are carried out at end of life, as well as to increase the occurrence of donation within the province to fill the ongoing demands of organ and tissue acquisition. The purpose of this study was to describe how common organ and tissue donation is in our complex patient population.  

**Methods:** As part of standard practice, we routinely ask patients about their organ and tissue donor status on admission to our unit, which is documented on the patient’s medical history. Patients who express an interest in organ and tissue donation are referred to our unit social worker. Information is provided about the process and if interested, a referral is then made to the Comprehensive Tissue Centre (CTC). The CTC obtains patient consent, determines eligibility and completes the necessary documentation to secure a donation at time of death. As of June 2011, we began documenting all of these referrals.  

**Results:** In the first four months of this project (June-September, 2011), there were 48 deaths on the TPCU. Of this total, there were 9 referrals for organ and tissue donation. For two of the 9 patients, there was a successful cornea donation at time of death. Seven patients were ineligible due to sepsis and recent chemotherapy. Further analyses to compare the TPCU donations with donations in other parts of the hospital will be conducted.  

**Conclusion:** The progressive debilitating trajectory of a terminal disease may prevent patients from donating specific organs and tissue, other than corneas. Future research will be directed towards understanding other challenges for this practice.

**Abstract number:** P359  
**Abstract type:** Poster  
**Quality of Care and Quality of Dying of Nursing Home Residents with Dementia, as Judged by Next of Kin: A Comparison between Flanders and the Netherlands**  
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**Research aims:** Considering the growing number of people who will die with dementia in coming decades, the quality of care and dying for people who suffer from dementia is of utmost importance. There has been little attention for the opinion of the next of kin, for an international perspective. We studied and compared next of kins’ assessment of quality of care and dying of nursing home (NH) residents with dementia in Flanders and the Netherlands.  

**Study design and methods:** The next of kin of 95 Flemish and 248 Dutch deceased NH residents were included. In Flanders, data were collected retrospectively in 2010; in the Netherlands data were gathered partly prospectively and partly retrospectively between 2007 and 2010. In both countries structured written questionnaires were filled in by a next of kin, invited by the participating NH. The next of kin were asked about their perception of quality of care and quality of dying, and satisfaction with care. We compared differences between countries in ordinal or logistic regression analyses adjusted for demographics and other possible confounders.  

**Results:** Few differences in satisfaction with care, and perceived quality of care and dying were found between the countries. For example, Dutch and Flemish next of kin were equally satisfied with care at the end of life. The mean rating of the Comfort Assessment in Dying -End-of-Life in Dementia (CAD-EOLD) scale was higher for Dutch respondents (OR2.4; CI1.2-4.8), as were two of the four subscales: Physical distress (OR2.0; CI1.0-4.0) and Emotional distress (OR2.7; CI1.4-5.7). Flemish next of kin thought that meals in NHs could be improved more often as Dutch respondents (OR3.1; CI1.0-3.4).
Conclusion: Next of kins’ perceptions of quality of care and dying in Flanders and the Netherlands are similar, though some differences were identified. Specific areas of improvement were identified in both countries.

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Abstract number: P360
Abstract type: Poster

French Swiss Physicians’ Attitude towards Palliative Sedation: Influence of Prognosis and Type of Suffering

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Background: Palliative sedation is a last resort medical act aimed at relieving intolerable suffering induced by intractable symptoms in patients at the end of life. This act is generally accepted as being medically indicated under certain circumstances. A controversy remains in the literature as to its ethical validity. There is a certain vagueness in the literature regarding the legitimacy of palliative sedation in cases of non-physical refractory symptoms, especially “existential suffering”.

Objective: This pilot study aims to measure the influence of two independent variables (short/long prognosis and physical/existential suffering) on the physicians’ attitudes towards palliative sedation (dependent variable).

Methods: We used a 2x2 experimental design as described by Blondeau et al. (2005). Four clinical vignettes were developed (vignette 1: short prognosis/existential suffering; vignette 2: long prognosis/existential suffering; vignette 3: short prognosis/physical suffering; vignette 4: long prognosis/physical suffering). Each vignette presented a terminally ill patient with a summary description of his physical and psychological condition, medication, and family situation. The respondents’ attitude towards sedation was assessed with a six-point Likert scale. A total of 240 vignettes were sent to selected Swiss physicians.

Results: 74 vignettes were completed (30%). The medians ± SD were; 2.62 ± 2.06 (v1), 1.88 ± 1.54 (v2), 4.54±1.67 (v3), and 4.75 ± 1.71 (v4). Analyses of variance and post hoc tests indicated significant differences between « existential suffering » and “physical suffering” groups, independently of the prognosis (F = 12.342, P = .000).

Conclusion: The French Swiss physicians’ attitude towards palliative sedation is more favourable in case of physical suffering than in existential suffering. These results are in line with those found in the study of Blondeau et al. with Canadian physicians and will be discussed in light of the arguments given by physicians to explain their decisions.

Abstract number: P361
Abstract type: Poster

The Last Months of Life of People with Motor Neurone Disease in Mechanical Invasive Ventilation: A Qualitative Study

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In Italy 10-15% of patients who die with motor neurone disease (MND) are invasively ventilated with a tracheostomy (IV). Median survival was very variable in 3 different series were of 9, 20 and 40 months. Data about death trajectories or deterioration after the tracheostomy are rare and it is difficult to predict when a MND patient with IV will die and when a specialist palliative care service (SPCS) can effectively be involved.

Aims: To understand what happens in the final months of life of this population. Semi structured in-depth interviews with informal carers (IC) who looked after MND IV Pts who had died in last 10 years in Piedmont (Italy) were performed. Participants were chosen among the PARALS register. Sample was determined on going, at the saturation of the data. 19 interviews were performed between Sept-Oct 2011. All the events were audio recorded, transcript verbatim, coding and a following content analysis of the most significant results was performed.

Results: Mean survival after tracheostomy was 30 months (median 20). IC declared that the majority of the patients had not wanted to be tracheostomized before the procedure become inevitable, only 2/3 gave the consent for the invasive procedure and with the IV the individual quality of life (QoL) decreased in the majority of both patients and carers. All the IC whose individual QoL did not worsen had the support of private personal assistants for the care. A sudden death occurred only in 20% of patients. In last 4-6 months both IC and patients had the perception of a clear deterioration. In the same period cognitive and communication impairment, local infections and sepsis, pressure sores, and the need for indwelling catheters and sedative-analgesic drugs were reported in the majority of patients. This qualitative study provides new information on how MND IV patients died and about significant events that can trigger the last 4-6 months of life that is the usual time of SPCS provision in Italy.

Abstract number: P362
Abstract type: Poster

Adverse Events of Chemotherapy Near the End of Life

Abstract number: P363
Abstract type: Poster

Aims: The main purpose of the present ongoing study is to evaluate the Awareness, the Quality of Life (QoL) and the Spirituality in palliative care patients.

Methods: From June 2009 to July 2010 we examined 105 terminal cancer patients (M: 58, F: 47; range age: 32-90; mean age: 71.77). The research was performed through a Semi-structured Interview for the Psychological Assessment of Patients and two structured questionnaires: 1) the EORTC (European Organization for Research and Treatment of Cancer) QLQ-C15-PAL, and 2) the WHOQOL-SRPB (World Health Organization Quality of Life - Spirituality, Religiousness and Personal Beliefs).

Results: Regarding Awareness, 41.9% of patients are aware about the diagnosis, 33.3% are not aware, 8.6% are suspicious, 7.6% express the desire not to know, 4.8% are borderline and 3.8% are not evaluable; the 54.3% are not aware of their terminal condition, 23.8% are vaguely aware, 9.5% are suspicious, 6.7% are aware and 5.7% are not evaluable. Regarding QoL, our sample compared to the normative data shows lower significant score on Physical Functioning, Emotional Functioning and Global Health Status (p< .05); instead the following scales Fatigue, Dyspnoea, Insomnia, Appetite loss and Constipation present higher significant score (p< .05). Moreover, Spirituality domain reveals lower significant results on Awe, Whole, Strength, Peace, Hope and Faith scales (p< .05).

Conclusion: Our sample presents a critical QoL, showing poorer global status, physical and emotional functioning and with more symptoms. Most patients know the diagnosis but an important part is not fully aware; moreover, most of them are not aware of the terminal condition. Our patients demonstrate to have a less sense of participation to spiritual dimension. The results of this study, although observational, underline the importance of a global approach in the terminal phase of illness able of answering to the complexity of this moment of life and its multidimensional needs.
Methods: Retrospective case note audit of 163 consecutive adult patient deaths (excluding dead on arrival). Data extracted and analysed using Microsoft excel.

Results: Mean age 73.8 years (22-99), mean admission 19.2 days (0 - 120). Commonest reason for admission was sepsis 45(28%), however 79(48%) of patients had more than one significant underlying medical condition 34(21%) had >2. 53(33%) had underlying malignancy. 143(88%) had DNAR orders, 1 patient had an advanced decision to refuse treatment. Ceiling of intervention documented in 94(58%). 72(45%) had no documentation of communication with carers, of these 51(70%) had DNAR orders. 39(24%) deaths were on the LCP, mean length of time on LCP 48 hours (0-11 days). PPC recorded in 25, 22 as part of LCP documentation. When on the LCP, PPC hospital 13(52%), home 7(28%), PPD Hospital 11(44%) Home 3(12%).

Conclusion: Despite limitations of retrospective case note studies this audit is important. Doctors are recognising dying in most patients; signing DNAR and documenting ceiling of intervention. There is evidence of room for improvement in relation to ACP and communication documentation. PPC and PPD was recorded in 15% patients most on LCP, representing the dying phase of illness. The PPC data documented differs considerably from national figures PPC hospital 12% home 58%. This may reflect sample size but could represent a change of preference in PPC or PPD in relation to ACP and communication documentation. There is evidence of room for improvement in relation to ACP and communication documentation.

Results: We enrolled, from July 2010 to October 2011, 58pts; mean age 59 y-old (range 33-75); 23 were women. The main 4 primaries cancer diagnoses were: lung(22.4%), colon (19%), stomach(13.8%) and pancreas(13.8%). Cancer diagnosis was made < 2 years in 27.7%.Regarding Pap Score groupA(56.9%), B(25.9%) and C(15.5%).The SAHD mean was 4.5±4.6. Women had a mean SAHD of 6.3±5.6 and men 3.2±3.1, U=0.027(p< .05). Women and men also obtained higher scores in the HADS depression subscale, 9.5±5.6 and men 3.2±3.1, U=0.027(p< .05). Correlation between POS-QoL and WTHD Rho= 0.48(p< .05).

Conclusions: In general, there is a low WTHD in this sample. Women had significant higher WTHD and depression scores than men. The WTHD increases as the POS-QoL decreases.

Conclusion: Despite limitations of retrospective case note studies this audit is important. Doctors are recognising dying in most patients; signing DNAR and documenting ceiling of intervention. There is evidence of room for improvement in relation to ACP and communication documentation.
Family Satisfaction with End of Life Care in a Tertiary Referral Cancer Centre

Abstract number: P368
Abstract type: Poster

**Background:** Anxiety & depression in advanced cancer patients (pts) had been related with functional impairment. **Aim:** To assess the relationship between anxiety & depression, and functional state decline in advanced cancer pts admitted in an Acute Palliative Care Unit (APCU).

**Patients and methods:** Advanced cancer pts admitted to the APCU willing to participate and gave their consent were enrolled. Anxiety & depression were evaluated using Hospital Anxiety & Depression Scale (HADS), dependency was assessed with Barthel Index (BI) & performance with the Karnofsky Performance Scale (KPS). Palliative Care Outcome Scale-quality of life subscale (POS-QoL) and Pap Score was assessed all patients. The study was approved by the Ethic’s Committee.

**Statistics:** A standard descriptive analysis was carried out. To assess the differences between sexes U Mann-Whitney test was used. To assess the correlation between scores Spearman’s correlation coefficient was calculated.

**Results:** We enrolled, from July 2010 to October 2011, 58pts; mean age 59 y-old (range 33-75); 23 were women. Main 4 cancer primaries were: lung (22.4%), colon (19%), stomach (13.8%) and pancreas (13.8%). Cancer diagnosis was made < 2 years in 27.7%. Regarding Pap Score group A(56.9%), B(25.9%) and C(15.5%). Correlation between HADS depression subscale & POS-QoL was Rho=0.28 (p< .05). Correlation between BI & HADS depression subscale was Rho= -0.26(p<.05), correlations between BI & KPS was Rho=0.85 (p< .01) and between BI & POS-QoL was Rho= -0.41 (p< .01). Correlation between Pap score & HADS anxiety subscale was Rho= -0.39 (p< .05). There were not found other significant correlations between HADS anxiety and other variables.

**Conclusions:** Depression is well correlated with the performance status decrease and the increase of dependency, as well as lower quality of life perception. Better prognostic survival is correlated with less anxiety.

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**Introduction:** The majority of patients dying in the UK do so in hospital (56%). In 2007, the Care Quality Commission reported that the majority of complaints regarding acute hospitals related to end of life care and bereavement. It is therefore important to determine family member’s views on the care of patients who die in hospital to improve care/services in the future.

**Aims:** To determine bereaved family member’s satisfaction with the care of patients dying in a tertiary referral cancer centre.

**Methods:** Prospective postal survey of all next of kin of adult patients who died as inpatients over a 1 year period (August 2010-2011). The questionnaire, sent at least 3 months after death, included the validated FAMCARE tool alongside questions about the patients and family member’s preferences regarding end of life and free text. Thematic qualitative analysis will be performed on free text.

**Results:** There were 219 inpatient deaths. Of these, 131 next of kin have been contacted by post. Forty eight have yet to be contacted (it is less than 3 months since death). The remaining 40 were excluded because the contact address was outside the UK, the contact details were incomplete or the cancer diagnosis was confirmed after death. To date, fifty six (43%) have agreed to complete the survey and 32 (25%) surveys have been returned.

It is anticipated that by May 2012 this study will be complete, with outcomes to be presented including Preferred Place of death for patients and family members, FAMCARE satisfaction scores and qualitative analysis of free text comments.

**Conclusion:** Although it is known that the majority of patients would prefer to die at home currently in the UK most still die in hospital. It is important that we strive for excellence in end of life care regardless of setting, and family member satisfaction is one method of assessing to quality of care to enable improvements in the future.
Introduction: In the UK the majority of patients wish to die at home (59-90%) but actually die in hospital (56%). It is known that certain patient specific, disease specific and environmental factors are associated with an increased likelihood of dying at home. In order to improve the number of patients dying outside hospital it is important to determine whether any additional factors to those reported in the literature influence the place of death of cancer patients treated at a tertiary referral cancer centre.

Aims: To determine the factors influencing place of death of cancer patients.

Methods: This is a retrospective study of patients treated at a tertiary referral cancer centre who died in the year April 2010-2011. Patients were included in the analysis if they were age > 18 and had been seen at hospital in the last 6 months prior to death. Binary logistic regression was used to determine significant factors effecting place of death. Factors considered include; age, gender, deprivation index, length of disease, time from last contact with the hospital to death, time from last treatment to death, palliative care team involvement.

Results: A total of 1651 patients died were analysed. The mean age was 66 years old (SD 14.01). 48.8% (805) were male. The marital status 935 (56.6%) married, 215 (13%) single, 220 (13.3%) widowed, 144 (8.7%) divorced and 137 (8.3%) not disclosed. The main cancer diagnoses were Gastrointestinal 373 (22.6%), Lung 249 (15.1%), Urology 246 (14.9%), Gynaecological 111 (6.7%), Breast 221 (13.4%). Of those in whom place of death was known, 238 (22.8%) died at home, 351 (33.7%) in hospital, 410 (39.3%) in a hospice, 29 (2.8%) in a nursing home, and 14 (1.4%) in other locations. We are currently following up the place of death for 609 patients (36.9%). Data quality and missing data are now being checked in preparation for binary logistic regression analysis. Full results will be available by May 2012 for presentation at the conference.

Abstract number: P370
Abstract type: Poster

Hospice Polypharmacy

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Background and hypothesis: End-of-life care refers to medical care of patients with a terminal illness or condition that has become advanced, progressive and incurable. We hypothesized that upon transfer the patient to hospice the drug arsenal is simplified focusing on symptom management and less emphasis is given on continuing routine medical interventions for diseases other than cancer.

Patients and methods: Records of consecutive cancer patients treated at two hospices in Finland in 2010 were studied. All medication was recorded at five time points, at the time of transfer, 2nd hospice day, 2 weeks and 2 months and one day before death. The data was coded in excel and statistical analyses were carried out using SAS system for Windows, Version 9.2 (Sas Institute Inc, Cary, NC, USA).

Results: There were 50 men and 88 women, with the mean age of 74.8 (48-94) and 74.8 (38-102). The length of stay at the hospice was 14 days median, range 2 to 376. The most common cancer was gastro-intestinal cancer (33%). In addition to cancer, most patients had history of other diseases. Cardiovascular and cardiac conditions were the most common ones (103 patients, 77%). All but 14 patients were treated with strong opioids for pain, and all but one of the 14 received weak opioids at least occasionally. Throughout the hospice stay and one day prior to their death most patients continued receiving medication for non-cancer conditions from several drug categories; 49 (36%) of one, 31 (23%) of two, 20 (15%) of three, 12 (9%) of four, 11 (8%) of five, two (1%) of six drug categories.

Conclusion: Polypharmacy was common among patients treated at hospice for terminal stage cancer, some of it needed for symptom control. Future study should assess justification of continuing polypharmacy for asymptomatic disease conditions since drug adverse effects and interactions may contribute negatively to life quality at the end-of-life care.

Abstract number: P371
Abstract type: Poster

When the Music’s over, Turn out the Lights - End-of-Life Wishes of Homeless Persons in Germany

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Background: Little is known about wishes for end-of-life care (EoLC) of homeless persons (HP). An American study undertaken by Song et al. (JGIM 2007;22:435-441) suggested that HP have many concerns about issues concerning their own death. We hypothesized that HP in Germany also have detailed wishes and fears concerning EoLC. The aim of this study was to explore these in order to identify themes which could be important for a needs-based provision of EoLC.

Methods: Strategic literature search, translation of the semistructured interview (INT) guide of Song et al., slight amendments following a focus group discussion with representatives from HP services in Germany. Pretest in 08/2010.
Results: From 11/2010 - 01/2011 15 HP were interviewed (age 47.2±13.5 (25-73) years; 86.7% male); mean INT length 33:52±10:40 min. EoLC domains: life-prolonging treatment, suicide, dying alone, romantic freedom, dignified death, being remembered, pain, trust in professionals/ welfare state, awareness of death, emotional coldness. Even though some categories matched those found by Song et al., the participants in our study showed little concern about death and dying. As a probable explanation, we found that the EoLC categories were deeply influenced by underlying domains (autonomy, dignity, trust and fatalism).

Conclusion: The results of our study give an insight into an unexplored matter in Germany. In comparison, we found a more positive experience with the welfare system, trust in provision of EoLC by the state and in health care professionals (HCP). HCP should help to increase awareness of EoLC matters among HP.

Abstract number: P372
Abstract type: Poster
Is Withdrawal of Antidiabetic Treatment in Dying Patients Associated with Distressing Symptoms? A Literature Review of Available Evidence

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**Aims:** Futile medications should be discontinued in patients approaching death. Diabetes (DM) is common and both hyperglycemia and hypoglycemia can be associated with distressing symptoms. It is unclear whether the withdrawal of antidiabetic treatment (ADT) leads to distressing symptoms that could increase the discomfort of the dying patient.

**Methods:** As part of Opcare9 a literature search of PubMed was conducted. All papers published in the English language that contained data on symptoms, reactions or events associated with withdrawal of ADT were reviewed.

**Results:** Original data specifically concerning problems associated within discontinuation of ADT in dying patients were scarce. Most published studies were done in patients not suffering from any terminal illness but rather undergoing treatment of chronic or acute medical conditions. Studies in non-terminally ill type II DM patients indicate that oral antidiabetic drugs as well as insulin can probably be safely withdrawn provided a good metabolic control prior to discontinuation. Likewise, routine blood glucose monitoring will no longer be necessary in dying patients with type II DM. This is in agreement with published consensus documents. Avoiding hypoglycemia should be prioritized in these patients. A history of many years of insulin use in multiple daily doses or (less common) previous ketoacidosis could imply a truly insulin-dependent DM type II and should be cautiously considered. While no original studies in dying patients with type I insulin-dependent DM have been published, consensus expert documents favor continued insulin therapy and blood glucose testing to prevent symptoms of ketoacidosis. No studies have investigated which insulin regimen is optimal in late palliative patients.

**Conclusion:** Due to the lack of original studies of how to manage ADT in this context research initiatives should be undertaken in order to improve the evidence-based care of dying patients with DM.

Abstract number: P373
Abstract type: Poster

**Shared Decision Making at the End-of-Life in the Hospital**

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In the Netherlands 30,000 people die each year in the hospital. There is growing interest in palliative care and adequate end-of-life (EoL) decision making in hospitals but in clinical practice this mainly involves cancer patients. In this study we investigated similarities and differences in EoL decisions for cancer and non-cancer patients in the hospital.

All general wards (17) and a unit for palliative oncology care in a Dutch university hospital participated in this study. For every adult patient who had died at one of the wards after having been admitted > 6 hours prior to death, physicians were asked to complete a questionnaire.

Between June 2009 and February 2011, we received 225 questionnaires. The median age of the deceased patients was 67 years, 56% were male and 49% had cancer. The median length of the last hospitalization was 11 days. During the last month of life, physicians more often discussed EoL treatment options with cancer patients than with non-cancer patients (euthanasia: 22% vs 6%;* palliative sedation 41% vs 12%;* intensive symptom control...
Abstract number: P374
Abstract type: Poster

End-of-Life Decisions in the Hospital; What Do We Know about Patients Preferences?

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In the Netherlands 30.000 people die each year in the hospital. When cure or recovery can not be obtained anymore complex medical decisions are often needed. In this study we investigated preferences on end-of-life (EoL) care of patients who died in the hospital.

Physicians were aware of the imminence of death in the large majority of all patients (89% and 83%); no differences between both groups were found in the moment of such awareness. However, physicians discussed imminent death with 67% of cancer patients and with 35% of non-cancer patients*.

In the dying phase cancer patients were more often treated with opioids (82% vs 61%*) and with continuous palliative sedation therapy (35% vs 19%*).

We conclude that physicians often recognize imminent death, both in cancer patients and in non-cancer patients. Nevertheless, discussion of imminent death and EoL decision making is more common in cancer patients than in non-cancer patients. Shared decision making at the EoL could be further improved, especially for non-cancer patients.

* Chi-square, p< 0.05

Abstract number: P375
Abstract type: Poster

Parenteral Nutrition in Palliative Care (PC): Utilization and Ethical Point of View

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Aims: To study parenteral nutrition’s (PN) utilization in a Palliative Care Unit (PCU)
Method: Retrospective study on charts on decision making about PN during a 6 months period in a PCU.
Results: 80 patients were included (44 females), 13 received PN. Mean hospital stay was 23 days. For 84% discharge mode was death. Mean PN intake was 776 kCal/d. PN was initiated in our unit for 5 patients with a mean duration of 13 days with a wide range from 2 to 30 days. Mean period without PN before death was 3 days. Collective discussion about PN withdrawal was found in 77% of our charts. The reason for withdrawing was either a non-favorable risk-benefit ratio (31%) or a complication (31%) or a dysfunctional route for PN (15%).

Discussion: Our study shows a small rate of patients receiving PN in PC. PN was initiated in only 6% of our patients. Clinical estimation of survival length below 1 month by the clinician was the major criteria for non-initiation of PN. Mean duration of PN is short. Mean energy intake thru PN is low for patients potentially under-nourished or in a hyper catabolic state. Patients didn’t benefit from PN because mean duration was below 1 month and we know from literature that PN can be beneficial only if maintained more than 1 month. We noted few arguments within the patients’ charts that justify initiation or withdrawal of PN in our PCU. We should improve the selection of patients that could benefit from PN. Furthermore, there was no anticipation in the decision making of PN withdrawal.
and clinical state impairment or a complication were the only reasons for PN withdrawal. The limit of our study is because of its retrospective nature and the small sample size the fact that we could not make any statistical analysis.  

**Future developments:** Based on our study and literature analysis, we propose a decisional algorithm to provide help in decision-making in the instauration or the withdrawal of PN in PC. This clinical tool should be evaluated in further studies.

**Abstract number:** P376  
**Abstract type:** Poster  
**Development and Preliminary Evaluation of the King’s Psychosocial Assessment and Care (K-PACE) Tool: To Improve Palliative Care in Critical Care Units**

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**Context:** More than one in five people admitted to a critical care unit will die there (Azoulay et al., 2009). Research has highlighted concerns about support for patients and families and decision making.  

**Aim:** To develop and evaluate a tool to improve palliative care in the critical care unit (CCU)  

**Setting:** One London teaching hospital with three CCUs (two general, one liver specialist) with an annual 1350 admissions.

**Methods:** Medical Research Council guidance for Complex Interventions. Phase I comprised intervention development, theoretical modelling, observation and qualitative interviews and focus groups with staff and families exploring concerns and view of interventions identified in literature review. Phase II comprised implementation and evaluation of tool feasibility and effects using staff survey, observation, audit of records and relative survey.

**Results:** Phase I: 47 staff and 24 relatives were interviewed. The short time between decisions for treatment withdrawal and death, plus concerns for support, symptom management, communication and decision making, highlighted a need to ensure excellent psychosocial assessment for all. Thus, as part of integrated care guidelines, we developed the King’s Psychosocial Assessment and CarE tool (K-PACE). K-PACE is used for all patients entering CCU, completed within 24 hours of admission. Phase II: Educational training supported K-PACE which was implemented in two waves. Post implementation survey of 95 ICU staff found that most (80%) were aware of K-PACE. 82% of nurses but only 17% of doctors had completed the tool. 158/213 (74%) relatives responded to the survey (additionally 3 patients responded), there were high levels of satisfaction for symptom control and psychosocial care but concerns continued regarding explanation of treatment and care.

**Conclusion:** K-PACE is a feasible tool to improve the palliative care of patients and their families in the CCU. Methods are developed for evaluation.

**Abstract number:** P377  
**Abstract type:** Poster  
**Developing a Primary Palliative Care Pathway**

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**Aims:** Guidelines, helping caregivers in tackling many challenges while caring for palliative patients, are seldom translated in a comprehensive, interdisciplinary Palliative Care Pathway (PCP). The ‘Liverpool Care Pathway’ is only applicable during the dying phase of the patient. A project supported by the Flemish Government, wants to develop and implement a PCP as an instrument facilitating the delivery in the primary care setting of good palliative care by a professional and multidisciplinary team to patients with a limited life prognosis of less than a year.

**Methods:** The PCP has been developed by a university research group, following a strict methodology. At different stages during the proceedings feedback was provided by different working groups, assuring a narrow cooperation with the primary care working field. After finishing a draft version, a pilot study was performed evaluating feasibility and acceptability of the PCP in the primary care field. Implementation of the PCP in 2012 will be accompanied by an intense educational support programme.

**Results:** This PCP has been designed as a small booklet resulting in a flowchart and a structured care dossier. An accompanying manual is available for the caregiver. The patients will be included by their general practitioner on the basis of the Surprise Question (SQ) and the Palliative Performance Scale (PPSv2). All patients, regardless of the kind of diagnosis, but having a prognosis of less than one year, should be included. Results of the pilot testing will be provided during the conference.

**Conclusions:** A PCP has been developed to facilitate the delivery of high quality, interdisciplinary palliative care in the primary care setting. Inclusion of patients should be
considered much earlier in the disease trajectory than just at the moment of the dying phase. Checklist and care dossier intend to be an aid for good quality of care and for good cooperation with patient, family and between caregivers.

Abstract number: P378
Abstract type: Poster

Preliminary Study of Problems Encountered by Staff in Implementing Version 12 of the Liverpool Care Pathway in a Spanish Hospice, Highlighting the Need for Ongoing Training

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Introduction: In May 2011, the Cudeca Hospice commenced using version 12 of the Liverpool Care Pathway (LCP) to improve care of patients in the last stages of their lives. The translation process had been completed according to the validation process of the Marie Curie Palliative Care Institute, (MCPCI) Liverpool. Version 11 had previously been used in the Hospice.

Research aims: Detect training needs of staff using the tool.

Study design and methods: During a pilot period of five months, twenty LCP forms were completed by staff working on the Hospice In-patient Unit. An introductory training session for the multidisciplinary team (Drs, nurses, auxiliary nurses, psychologists, social workers and physiotherapist) had previously been carried out. An analysis of the 20 forms was based on: comprehension of the tool, congruence of the response, rigor in completing all the items of the tool. The data collected was according to the Post Implementation Audit required by MCPCI to finalise the process permitting Cudeca Hospice to use the tool.

Results: 90 patients had died in the In-patient Unit during the pilot period; only 20 LCP forms had been used. Only 8 of those LCP forms had been correctly used, 50% had not completed all the data of care after death, 25% had minor faults. Others showed gaps in understanding the terminology and incongruence with the registration of variances and above all, not registering all the details needed to complete the tool.

Conclusions: It is fundamental that all the staff implicated, after an initial impregnation session, have ongoing training, this should include new members of staff. Training should given on criteria of recognition that a patient is in the last stage of life. That there are key workers available to answer queries during use. That management give clear indications about the importance of the implementation of the tool.

Abstract number: P379
Abstract type: Poster

Preference for Active Ending of Life in Older People in the Last Three Months of Life; Relation with Advance Euthanasia Directives and Requests for Euthanasia

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Background: It is unknown whether preferences about active ending of life in certain situations (that involve severe suffering from disease) are consistent over time. Therefore we studied preference about active ending of life at three months and at three days before death, and how this preference relates to advance euthanasia directives (AED) written in the past and to actual requests for euthanasia.

Methods: Retrospective cross-sectional quantitative study of deceased members of two cohort studies: the Longitudinal Aging Study Amsterdam (LASA), representative for the Dutch older population (8% having an AED) and the Advance Directive Cohort (ADC) consisting of people with an AD (82% also having an AED). Participants were proxies (LASA n=168; ADC n=184) of deceased cohort-members aged 57 and over. Data were collected using a structured written questionnaire.

Results: Three months before death, 15% of the LASA sample had a preference for active ending of life under certain circumstances; people with an AED had such a preference more often than those without an AED (85% versus 15%). Preferences rarely changed between three months and three days before death. Of the subjects with a preference for active ending of life 45% eventually requested euthanasia; almost one third of these requests was granted.

Conclusion: Only a minority of Dutch older people have a preference for active ending of life in certain situations. Preferences about active ending of life were stable in the last three months of life and correlated with the presence of a previously written AED. Just over half of subjects with a preference for active ending of life did not request for euthanasia or physician-assisted suicide. Possibly their situation differed from the situation in which they would want active ending of life; or their opinion about the situation in which they would prefer ending of life may have changed.

Funding: Netherlands Organization for Scientific Research (NWO)

Abstract number: P380
Abstract type: Poster

Geographical Variation in Hospital Mortality - Does where You Live Determine how You Die?
Abstracts

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Most previous analysis in this area has concentrated either on Office of National Statistics (ONS) data or national Hospital Episode Statistics (HES) data.

Aim: This study investigates geographical variation in underlying causes of death (CoD) for people that die in hospital by Local Authority in England.

Methods: Our study links Office of National Statistics (ONS) mortality data to Hospital Episode Statistics (HES) admission data. The ONS and HES linkage provides a longitudinal view of the hospital services received in the month before death and provides accurate CoD information not available in HES.

Results: Approximately 60% of all deaths occur in hospital, 45% die in hospital during an admission of ≤30 days. We analysed variation by CoD and Local Authority (LA) of residence. Examples of the LA variation in proportions of deaths occurring in hospital in the last month of life include; Cancer (18-68%), Cardiovascular (20-47%), Stroke (25-67%) and Respiratory (26-67%). By identifying and investigating variation in; Cancer, Stroke, Cardiovascular and Respiratory deaths, this study will inform policy and planning decisions concerning the nature of patients needs in their final month of life.

Abstract number: P381
Abstract type: Poster

How Using Secondary Data Sources Can Enhance our Understanding of End of Life Care

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Aim: 1. To understand range and complexity of data sources currently available on end of life care;
2. How to best use data sources to inform needs assessment, and service planning and evaluation;
3. Areas where existing data is limited and needs further development.

Background: The South West Public Health Observatory has recently undertaken a systematic review of available data sources on end of life care. The compendium of data sources is now available on the NEoLCIN website. This resource enables commissioners to undertake needs assessments, to plan services, and to assess aspects of the quality of local care provision. Indeed, this resource has already been used by professionals, since its launch in June 2010, with 1,679 different individuals visiting the compendium.

Methods: A systematic review of routine data sources on end of life care. Resources were reviewed for their relevance, coverage, temporality and timeliness, completeness, and representativeness. A web-based tool was launched on the NEoLCIN website.

Results: The measure, ‘The percentage of all deaths that occur at home’, has been adopted as a national indicator (N129). To date 59 unique data sources have been identified held by 15 organisations, covering 14 topics. Data sources are available on service infrastructure, demography and disease trajectories. Service infrastructure sources include: hospice care (2), palliative care in hospitals (3), primary care (2), residential and nursing homes (8), social care (19), emergency hospital care (1) prison (1), and carers (5). Nine data sources can be used for the assessment of population change in terms of size, composition, and health status. Eight data sources provide data on illness and disease progression, to further understand place and quality of death.

Conclusion: For the first time, data sources on end of life care have been assessed and are now available on one site.

Abstract number: P382
Abstract type: Poster

New Insights into Place of Death for People with Alzheimer’s Disease, Dementia and Senility

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Background: Between 2001-09, 15% of all deaths in England had a mention (i.e. either an underlying or contributory mortality coding) of Alzheimer’s disease, dementia or senility. Over this period there was a 57% increase in the number of mentions from these conditions.

Aim: This analysis specifically examined the age and sex distributions and places of death for each of these conditions, by whether they were coded as underlying or contributory.

Results: Major differences were found in age distribution, gender balance and place of death across these conditions, and there was also marked variations across these factors according to whether the conditions were recorded as underlying or contributory causes of death.

The analysis then went on to examine patterns and effects of contributory codings of Alzheimer’s disease, dementia and senility for major underlying cause of death groupings (circulatory diseases, malignant cancers, respiratory diseases) and found large differences across these groups. Place of death of each of these major groups was also examined according to whether contributory codings of Alzheimer’s disease, dementia or senility were present, and radical differences observed between populations with and without contributory codings.
Conclusions: As the number of people with Alzheimer’s disease, dementia and senility is projected to increase by over 70% in England between 2010 and 2030, these conditions are set to become increasingly important, both in terms of numbers of persons affected and resources consumed. Greater insight into the patterns and trends of these conditions is therefore essential to plan the provision of appropriate levels and patterns of care.

Abstract number: P383
Abstract type: Poster
Deaths in Older Adults in England

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An understanding will be gained of differences in cause and place of death in older adults (people aged 75 and over) and the factors that influence these, such as age and sex. It is important to understand the types of care that will be required by older people at the end of life since two-thirds of deaths are in people aged 75 and over and, in the future, the proportion of deaths in the oldest age groups are predicted to increase further.

We will present key results from the report, ‘Deaths in Older Adults in England’ produced by the South West Public Health Observatory on behalf of the National End of Life Care Intelligence Network. This report describes differences in place and cause of death in older people and is part of work to provide information and evidence to support the End of Life Care Strategy.

The report analysed deaths in people aged 75 and over registered in England in 2006-08 (source: ONS mortality data). There were differences in underlying cause of death and place of death according to age and sex. In people aged 75 and over, a higher proportion of deaths in females were from pneumonia (organism unspecified), stroke and dementia compared with males. Deaths from senility and dementia were more common with increasing age. In people aged 75 and over, a higher proportion of deaths in females were registered in hospital or in their own residence, while a lower proportion of males than females died in nursing homes and old people’s homes.

It is important to consider the implications of these findings when planning end of life care services as two-thirds of deaths in England are in people aged 75 and over and, in the future, the proportion of deaths in the oldest age groups are expected to increase further.

Abstract number: P384
Abstract type: Poster
Effectiveness of the Program for Comprehensive Care of Patients with Advanced Illnesses in Spain

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Research aims: Evaluation of the effectiveness of psychosocial intervention of the program for comprehensive care of individuals with advanced diseases and their families, started three years ago, with a funding initiative from the social responsibility area of one of the main saving banks in Spain. Its aim is to promote psychosocial and spiritual care, in order to generate evidence to be considered in the Spanish National Strategy for Palliative Care.

Study population: Adults with advanced diseases cared for by psychosocial teams acting as support for palliative care professionals.

Study design and methods: Quasi-experimental, prospective, multi-centric, one-group pre-test/post-test study. Effectiveness assessment will be performed after a baseline visit and, at least, one follow-up visit. Psychosocial intervention in wellbeing, emotional adaptation, anxiety, suffering, family communication, life significance and peace will be evaluated.

Methods of statistical analysis: Continuous variables include number of non-missing observations, mean, standard deviation, and standard error of mean, minimum, median, maximum. Categorical variables include number of non-missing observations and column percentages. T-Student constrast and Wilcoxon Signed Rank Test will be applied to analyze the significance of differences between assessments.

Results: More than 20,000 individuals cared for by 29 psychosocial teams. Evaluation at 18 months: significant improvement in wellbeing and emotional adaptation; decrease in anxiety and suffering. No significant improvement has been found in family communication, life significance and peace. Evaluation at 30 months: statistical analysis currently ongoing. Final results will be available in November 2011.

Conclusion: Proposed model can be effective in improving psychosocial care of patients with advanced illnesses.

Funding of the study: Obra Social “la Caixa”

Abstract number: P385
Abstract type: Poster
Nutrition and Hydration at the End of Life - An Evaluation among Nurses, Physicians, Patients and Relatives on a Palliative Care Unit at a University Hospital

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Aims: Withdrawing nutrition and hydration in the last days of life are still controversially discussed among physicians.
Many physicians admit that they have not been properly instructed in end of life decisions. That may causes troubles since the physicians are the persons in charge to make the final decision of withdrawing hydration and nutrition. Therefore, we wanted to know how safe physician and nurses feel with these decisions and secondly, what the patients and the relatives expect.

Methods: We have distributed standardised questionnaires to physicians, nurses working at the university hospital and to patients and relatives in a palliative care situation. We asked for atrifical nutrition and hydration at the end of life, decision making, communication, religios aspects, and legal issues.

Results: Within one year we collected the questionnaires of 99 nurses and 49 physicians as well as 39 patients and 28 relatives. The main results show a high incertainty in end of life issues especially with hydration and nutrition when physicians are asked as compared with nurses. Often religios aspects and putative legal issues restrain physicians from withholding fluid and nutrition. Physicians are more doubtful as patients in this situation. Patients and relatives have almost the same preferences in end of life decisions

Conclusion: This study showed that there is still incertainty in withholding nutrition and hydration at the end of life. Therefore, education in end of life care is important before physicians are confronted with this situation.

Abstract number: P386
Abstract type: Poster

A Prospective Study of the Risk Factors for Falls in Patients with Advanced Cancer

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Aims: The small number of studies of falls in patients with cancer have revealed higher than average rates of falls in palliative care and oncology inpatient settings but were limited in their capacity to identify risk factors. The aims of this study were to identify the incidence of falls and risk factors for falls in adults with advanced cancer.

Methods: Consecutive admissions to community & inpatient palliative care services with metastatic or locoregionally advanced cancer able to mobilise unassisted were recruited. A research assessment & questionnaire were conducted at baseline. Outcome measure: time to fall in days, determined by weekly telephone contact for 6m or until time of fall or death if occurs< 6m. Relationship between independent variables and time to fall was examined using Cox proportional hazards model. Variables with statistically significant univariate hazard ratios were included in a final multivariate model, fitted using stepwise selection, using p< 0.05 and p>0.1 as limits for variable entry and removal.

Results: 185 participants(52.4% male, mean age 68±12.6yrs), 93(50.3%) experienced a fall during follow-up; 35/66 (53%) of participants aged < 65 years and 58/119(48.7%) of participants aged ≥65 years fell. Injuries; 35/93 soft-tissue injury, 3 fractures, 1 dislocation. The presence of a primary brain tumour or metastasis (HR 2.5 p=0.002), number of falls in the preceding three months (HR=1.27 p=0.005), severity of depression (ESAS) (HR=1.12 p=0.012), daily benzodiazepine dose (HR=1.05 p=0.004) and having cancer related pain (HR=1.96 p=0.024) were independently associated with time to fall in multivariate analysis.

Conclusion: Falls prevention should be an integral component of advanced cancer care. Of the risk factors for falls in advanced cancer, benzodiazepine dose and depression are modifiable. Clinicians must be cognisant of the potential impact of management of anxiety and depression on falls risk in this population.

Abstract number: P387
Abstract type: Poster

A Cross-sectional Survey of the Activity Palliative Care Teams in Portugal

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Objective: To survey the activity of Portuguese palliative care teams.

Methods: All the 19 palliative care teams included in the website of the Portuguese Association for Palliative Care and more 2 were invited to participate in the survey. A questionnaire was sent to all those who accepted to participate to evaluate it for relevance and make suggestions for improvement. A new questionnaire was designed with the suggestions received. The study was
carried out on the 18th week of 2011. Each team filled out the questionnaire with the data of all patients seen in one day of that week. There was one day for each activity of the team.

**Results:** Of the 21 teams invited 10 actually participated in the study. 164 patients were included with a mean of 16 per team (4 to 32). The activities of the 10 teams were: inpatient care only - 3 teams; inpatient + outpatient care - 1 team; hospital support care + outpatient care - 4; hospital support care + outpatient care + home care - 2. Patients included were followed as: 53 (32%) inpatients in palliative care unit; 58 (35%) hospital support team; 32 (20%) outpatients; and 21 (13%) home care. The median age was 71 years with a range: 16 to 95. 51% were females. The illness most frequent was cancer: 151 (92%). The most common cancer was colorectal with 22 patients (13%), followed by gastric 17 (10%), head and neck 16 (10%), breast 15 (9%), and lung cancers 14 (9%).

**Conclusion:** The supply of palliative care is still scarce in Portugal. Hospital support care is the most common service carried out by palliative care teams. No one of the teams included ran a day centre. Cancer is by far the most common illness, as occur in many other places despite the claims that patients with many chronic diseases should as well be assisted by palliative care.

**Abstract number:** P388
**Abstract type:** Poster

**Survival beyond Six Months in an Egyptian Cancer Center-based Palliative Medicine Unit**

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**Introduction:** In lower-income countries, the majority of cancer patients presents in an incurable stage. Due to the limited resources, there are few anticancer treatment options and the only realistic treatment is palliative care (PC). In these circumstances, it may be possible to encounter relatively long-term survivors among PC cancer patients. Our aim is to estimate the prevalence of this group of patients in an Egyptian cancer PC setting and to determine possible predictive factors.

**Methods:** Review of the palliative medicine unit (PMU) registry in an Egyptian cancer center. Patients referred to the PMU from September 2008 to February 2011 were included. Patients were classified into two groups, group 1 (G1) patients who continued to follow with the PMU for ≥ 6 months and group 2 (G2) patients who died or lost to follow up within 6 months.

**Results:** During the study period, 855 patients were referred to the PMU. 143 (17%) patients survived for ≥ 6 months, 6 (4%) of them had no active cancer and were referred for symptom control. The most common cancer to survive ≥ 6 months in the PMU was pleural mesothelioma (28%) followed by breast (21%) and liver (19%) cancers. The estimated median survival of G1 patients was 482 days (95%CI: 397-567). Female gender, age < 55 years and first referral to PMU in the clinic significantly predicted survival for ≥ 6 months in the PMU (p = 0.036, 0.01 and 0.036; respectively). G1 patients were more likely to die at home compared to G2 (80% vs. 62%, respectively; p=0.023).

**Conclusion:** When anti-cancer treatment options are limited, a significant proportion of advanced cancer patients may be referred earlier to PC and survive relatively longer. For this group of patients, sub-acute PC models may be more suitable rather than exhausting the limited resources of acute care settings in Egypt. The predictive factors identified needs further validation. Future research is warranted to study this subgroup of PC cancer patients.

**Abstract number:** P389
**Abstract type:** Poster

**Epidemiology of Chronic Pain in Cancer Patients in Catalonia (Spain): Country-wide Study**

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**Aims:** To assess prevalence (Prv) of chronic pain (ChP) in cancer patient (pts) & related common factors, in Catalonia (Cat).

**Patients & methods:** Transversal study enrolling ambulant (Out) & hospitalized (In) adult cancer pts in 25 hospitals in Cat. ChP defined as pain lasting ≥ 2 wks. Study protocol was approved by ethic committees of all centres. Sample size was calculated assuming 50% pain Prv with 5% absolute precision & 95% confidence interval, 385 pts were needed for each In-pts and Out-pts.

**Results:** We included 1,064 pts, 627 In-pts and 437 Out-pts. ChP overall Prv was 55.3%; In-pts 64.7% & Out-pts 41.6% (p<.0001). By attending service ChP Prv was: Haematology
35.8%; Medical Oncology 47.1%; Radiotherapy (RTD) 71.4%; Palliative Care (PC) 79%. About sex, women (W) reported > ChP than men (M), 63.1% vs. 49.4% (p < .0001), this fact was kept on in Out-pts; W 54.8% vs. M 33.6% (p < .0001), but not In-pts. About age ChP Prv was 54.4% (20-45 yr-old), 55.1% (45-65), 54.6 (66-85)& 65.3% (>85). Given a 65 age cut-off, Prv was 54.8% (<65) vs. 55.6% (65) [NS]. ChP increases its Prv accordingly KPS decline; (100-90) 32.6%, (70-80) 55.8%, (50-60) 68.8%, (30-40) 73.9% & (20-10) 87.3% (p < .0001). About time from cancer diagnosis highest Prv (62.7%) was after 1-2 yrs. In solid tumours, ChP Prv increases in parallel with cancer spread; pts remission 31.5%, local 48.7%, regional 57% & metastatic 64.5%. Haematological cancer ChP Prv rises with its progress, but leukaemia. Pts on antitumoral treatment reported less ChP than those without (50.4% vs. 60.5%; p = .001). Pts on chemotherapy reported less ChP than those without (47.9% vs. 52.1%; p < .0001), by contrast pts on RDT reported more ChP (69.8% vs. 30.2%; p < .0001). Globally, In-pts reported more ChP than Out-pts.

Conclusions:
# ChP Prv increases with age, cancer spread & KPS decline.
# Due high ChP Prv expertise in pain management should be promoted specially in hospitalization, RDT and Palliative Care.

This study was granted by Marato TV3 Foundation

Abstract number: P390
Abstract type: Poster
Nursing Home Residents View of Ethical Challenges in Nursing Homes - First Results
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Aims of the study: The aims of the present study were to investigate ethical challenges in nursing homes from the residents’ perspective and to find out what patients perceive as ethical problems in nursing homes.

Background: There are many ethical challenges in nursing homes. Scientific knowledge about ethical problems and ethical decision-making in nursing homes is lacking for Norway and Europe.

Methods: Qualitative study with semi-structured interviews of nursing home residents. An interview setting with structured questioning and open interviewing was used. A number of 11 patients have been included in the study so far. The first interviews were used as a pilot study and the interview guide was changed and adapted as needed during the study. On ground of research ethics only participants with the ability to give full informed consent were included in the study.

Results and conclusion: 11 nursing home residents aged 74 - 100 years (mean 86) were included by nursing home staff (nurses or nursing home physicians). One informant was excluded by the researcher because of cognitive impairment which was diagnosed within the first minutes of the interview. The interview duration varied from 12 - 47 minutes.

Main topics brought up by the participants were: Lack of resources; Autonomy and self-determination; Respect; Relation to the caregivers; Acceptance and adaptation to the situation; Patience (“Do not complain”); Factors of well-being.

Our first results show that lack of resources, autonomy, respect and the relation to the caregivers are among the most important ethical challenges for the nursing home residents. As the study is ongoing, further interviews with residents and focus-group interviews of relatives will help to question our first results and to enrich the knowledge of the patients and relatives perspective on ethical problems in nursing homes.

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Abstract number: P391
Abstract type: Poster
The Reasons for Gatekeeping in Palliative Care Research: A Systematic Review
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Background: In order to provide palliative care patients with the best care possible, evidence based research is important. Gatekeepers often guard eligible patients from research participation and thus influence research recruitment. Because recruitment of eligible research participants is necessary for the improvement of palliative medicine, identifying the reasons for gatekeeping is crucial.

Aim: We did a systematic review to identify the primary gatekeepers in palliative care research, to categorize their reasons for gatekeeping and establish the common themes. The latter will assist us in the future design of an ethical guideline for healthcare professionals and highlights areas for future study.

Design: Systematic review

Methods: Medline, Embase, Google scholar, palliative care journals and cross-referencing were used to find relevant studies.

Results: We analyzed the current literature on gatekeeping and barriers to research participation in palliative medicine. We identified seven categories of gatekeepers in the process: GPs, oncologists, ethics committees, hospice
staff and management, patient groups, family members and the patient him/herself. The most common reasons for gatekeeping are: the conviction that the terminal patient will not benefit from research participation, concern about the patient’s vulnerability, concern about informed consent, concern that the doctor-patient relationship will deteriorate, lack of interest in the research purpose and concern about the ethical acceptability of research. Evidence shows, however, that terminally ill patients can benefit from research trials and often want to participate.

**Conclusion:** Further research is needed to evaluate strategies to better deal with gatekeeping-activities in palliative care research, in order to improve its evidence base.

**Abstract number:** P392  
**Abstract type:** Poster

**MORECare Research Methods Guidance Development: Recommendations for Ethical Issues in Palliative and End of Life Care Research**


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**Aim:** Research in palliative and end of life care (P&EoLC) is an issue of intense ethical debate. We aim to identify agreed best practice to accommodate ethical issues in research on P&EoLC.

**Methods:** We used the MORECare Transparent Expert Consultation approach to conduct consultation workshops with experts in ethical issues and P&EoLC research. Prior to workshops participants were sent overviews of pertinent issues in ethical issues and P&EoLC. Following workshop presentations and discussion, nominal group techniques were used to produce candidate recommendations. These were then rated online by participating experts. Descriptive statistics were used for analysis of consensus and rated importance. Narrative comments were collated.

**Results:** The workshop comprised 28 participants making 16 recommendations. The top three recommendations were:
1. Closer working and open communication between participants is required to increase awareness and understanding of P&EoLC research.
2. Respect is required for autonomous decisions of patients and carers regarding research participation and inappropriate gatekeeping and paternalistic attitudes needs to be avoided.
3. To incorporate wide inclusion criteria in studies, sensitive recruitment is required that demonstrates empathy, is responsive to an individual’s understanding and emphasises the voluntary nature of participation. The main area which failed to reach consensus was on the way informed consent should be obtained.

**Conclusions:** When designing studies in P&EoLC it is recommended that all research participants are aware of the need, as well as the challenges of P&EoLC research. Collaborative working between all those involved, flexible and enabling strategies are needed to be inclusive of the diversity of this population. Future studies need to document how research is carried out in order to refine the recommendations.

**Abstract number:** P393  
**Abstract type:** Poster

**The EAPC Ethics Taskforce’s Objections to Legal Euthanasia Revisited**

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**Aims:** In 2003 the EAPC Ethics Taskforce objected to legal euthanasia because it 1) might stunt the growth of PC and 2) put vulnerable patients at risk. How does the experience of 20 years of regulated tolerance in the Netherlands and 9 years of legal euthanasia in Belgium and the Netherlands (BeNe) inform these legitimate concerns?

**Methods:**
For 1): Analysis of direct and indirect indicators of PC strength from the EAPC report to the UK Commission on Assisted Dying, comparing BeNe with 4 countries where euthanasia is illegal and for 2): systematic review of the peer-reviewed literature.

**Results:**
1) An index with per capita numbers of PC units, beds, hospital support teams, home-care services, physicians, participants in EAPC conferences and Pubmed publications dealing with PC shows BeNe about=UK and a lower-ranking cluster with Spain>Germany>France. In BeNe PC grew markedly since 2002. The growth rate of PC in the comparison countries is less well documented.
2) Vulnerable patients are under-represented among euthanasia recipients. Indicators like increased impact of PC, more consultation before end-of-life decisions and decreased incidence of life-ending without explicit request suggest that the overall quality of end-of-life care has improved since 2002 in BeNe. Yet, several types of transgressions of the strict requirements of the euthanasia law are observed. Though unprosecuted, most became less frequent. The confidence of Belgians in their health-care system has increased from 87% in 1999 to 92% in 2008.

**Conclusions:**
1) Within limitations by differences in the organisation of PC and few data for comprehensive diachronic
Continuous Sedation until Death in Flemish Nursing Homes: Justifications and Objections of Physicians and Nurses

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Aims: Continuous Sedation until Death (CSD), the act of reducing or removing the consciousness of an incurably ill patient until death, is a prevalent practice in end-of-life care in Flemish nursing homes. Nevertheless, there is a clear lack of research on the experiences and perspectives of nursing home physicians and nurses regarding this far-reaching treatment. This study aims to explore and describe the circumstances under which they consider CSD to be justified, as well as the factors that influence their decisions on CSD.

Methods: Six focus groups were conducted including 10 physicians and 39 nurses working in either public or catholic nursing homes of varying size. One focus group included only physicians, two included only nurses, while the remaining three groups were a mix of both. All discussions were transcribed and subsequently analyzed using a thematic content approach.

Results: Both physicians and nurses stress that respecting the decisions of the patient is a matter of major concern in deciding for CSD. Life expectancy of the patient, which they find hard to estimate, is considered less relevant than severe suffering (even if this is mainly existential distress). The main objective is to provide a comfortable context for dying, even if this means the hastening of death. Dementia is regarded as an important constraining factor, as it impedes the evaluation of suffering. Finally, the influence of family members may further complicate the decision making process; during the administration of CSD, physicians and nurses often feel pressure from the patient’s family to hasten death.

Conclusion: The conditions under which nursing home physicians and nurses consider CSD to be justified are not entirely congruent with guidelines on CSD. Subjective opinions and personal ethics appear to play a significant role in the decision making process on CSD.

Abstract number: P394
Abstract type: Poster

‘Battling on’ and ‘Blinkered’: Carer Experiences of Home Based Care at the End of Life

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Background: The physical care needs of patients approaching the end of life are considerable and require specialist knowledge and skills amongst those who care for them. However, when hospice patients are discharged back home families often express concern as they receive no formal guidance on practicalities of physical care and instead adopt a ‘trial and error approach’ to palliative care. Such experiences create barriers in terms of the families’ self-perception of the care they provide, and can precipitate re-admission to hospital. This is not only problematic for the patient but also impacts upon carer wellbeing. A variety of psychological and physical health problems have been identified for carers, some of which are associated with carers’ perception of competence and the quality of care they provide.

Aims: To explore the experiences of carers and health professionals on end of life care provided in the home setting by informal carers.

Methods: We carried out 4 focus groups in September 2011, 2 with hospice based nurses and 2 with carers/ former carers of patients at the hospice. The group discussions explored experiences of, and views on, the challenges of providing care in the home setting, the information and training needs of carers and possible interventions.

Results: Thematic analysis of the data has indicated knowledge gaps and concerns amongst carers relating to practical care tasks e.g feeding, lifting, medication, and uncertainty over what support services are available and when and where to get help if needed. The data also provides examples of how such concerns impact upon carer wellbeing and adaptation (including bereavement experiences), and how carer and patient identities influence
service use and the possibilities for supportive interventions for carers.

**Abstract number:** P396  
**Abstract type:** Poster  

**How Caregivers Assessed the Service Provision of 7 Palliative Care Home Support Teams - Results of a Regional Study**

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**Aims:** Seven palliative care home support teams are implemented in the Austrian region of Styria. The study focused on the perspective of the caregivers: How do they assess the quality of the service provision? Did the teams meet the needs of the caregivers?

**Methods:** During six months the caregivers of all deceased patients with at least two home visits were included. Between 4 and 8 weeks after the death the caregivers were asked in a structured interview to take part in the study with an anonymous questionnaire. A descriptive statistical analysis was done.

**Results:** 338 of the 502 deceased patients fulfilled the including criteria minimum 2 home visits. Finally 290 caregivers with consent could be identified, to whom the questionnaires was sent. The rate of return was 80.0 %. The caregivers were highly content with the quality of the service provision: quick response / enough time during the first contact (both >99%); 94.2% were informed about the 24/7 telephone support and 55.1% used it. The given information during the course of the disease was assessed as very helpful and the way of personal communication was very much appreciated as well as the given practical support. The assessed quality of information given during the time of dying and bereavement was rather good. 75.4% of the caregivers had the impression that the time the patient could spend more time at home with due to the support and 67.4% stated that hospital stays were avoided. Only 4.1% of the 228 handwritten comments referred to improvement potential.

**Conclusions:** The main reason for the overall very high rated quality seems to be that the teams met the individual needs of the patients and the caregivers. The circumstance, that this support is not expected and free of costs may also be relevant for these results. The high numbers of written comments need to be analyzed qualitatively.

**Abstract number:** P397  
**Abstract type:** Poster  

**Male Carers’ Perceptions of Support for Adults with Multiple Sclerosis: Findings from a National Survey in the UK**

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**Background:** Multiple Sclerosis (MS) is more prevalent in women than men. Men are particularly likely to take on the role of carers in MS but this has been rarely researched. The EAPC Carer White Paper notes the paucity of research into carer sub-groups’ support needs.

**Aim:** To investigate the perception of support for adults with MS of men caring for adults severely affected by MS.

**Method:** Questionnaire survey design. Questionnaire developed from initial qualitative interviews and widely disseminated via UK MS Society.

**Findings:** 231 men took part (85% online, 15% by post). Most cared for an adult with Secondary Progressive (44.2%) or Primary Progressive MS (37%). Men lived in 45 UK counties, mean age was 60 years, and half reported spending at least 50 hours a week caring (52%).

A third (34%) had not tried to access advice/information about support/services. Of those that had, most found it ‘very’ (15%) or ‘fairly easy to find’ (54%). Men aged under 55 years reported most difficulty in accessing information (p=0.006).

Twenty five percent of men had received no support/services in the last year. Of the remainder, 67% reported the support/services had ‘made things easier’.

Most men reported the amount of support received ‘was about right’ (68%), and rated professional care staff as ‘completely’ (16%), ‘very’ (37%) or ‘fairly reliable’ (32%). Most men were ‘extremely’ (8%), ‘very’ (29%) or ‘fairly satisfied’ (30%) with support from social services. Those still working reported significantly more dissatisfaction than retired men (p=0.05).

**Conclusions:** Men were largely positive, but not effusive, about services/support available to them and the person
in their care. Younger men repeatedly differed in their perceptions, suggesting that they either have higher expectations, greater need or both. Health professionals need to consider the specific needs of men carers.

Abstract number: P398
Abstract type: Poster
Male MS Carers’ Perceptions of Support for Themselves: Findings from a National Survey in the UK
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Background: Multiple Sclerosis (MS) is more prevalent in women than men. Men are particularly likely to take on the role of carers in MS but this has been rarely researched. The EAPC Carer White Paper notes the paucity of research into carer sub-groups’ support needs.

Aim: To identify the perceptions of support for themselves of men caring for adults severely affected by MS.

Method: Questionnaire survey design. Questionnaire developed from initial qualitative interviews and widely disseminated via UK MS Society.

Findings: 231 men completed the questionnaire (85% online, 15% by post). The majority cared for an adult with Secondary Progressive MS (44.2%) or Primary Progressive MS (36.8%). Men lived in 45 UK counties and the mean age was 60 years.

Most men stated it was ‘quite easy’ (45.8%) to access support for their own needs but a quarter said it was ‘quite difficult’ (26.0%). Older (p=0.05) and retired (p=0.012) men had significantly less difficulty.

Many reported ‘no need’ (67.5%) but a quarter ‘would like’ (25.5%) some training. Men still working (p=0.05) and from Southern England (p=0.004) reported a greater desire for training.

Half the men had to initiate contact with ‘most’ of the services (50.0%) they needed and a quarter with ‘some’ (25.5%). Few received pro-active support from ‘some’ (15.5%) or ‘most’ (9.5%) of the services they needed. Men still working had significantly less pro-active support (p=0.05).

Men were divided having ‘no encouragement’ (38.1%), ‘some encouragement’ (34.1%), and ‘have encouragement’ (27.9%) respectively.

Most men (69.3%) had not taken a break from caring, for more than 24hrs, in the last year but many that did were ‘very satisfied’ (50.0%) or ‘extremely satisfied’ (19.2%).

Conclusions: Many men appear isolated and unable to take a break. Younger men still working had more difficulties and needs. Interventions are required to support health professionals pro-actively engage with male carers’ needs.

Abstract number: P399
Abstract type: Poster
A Study to Explore the Experience and Support Needs of Older Family Caregivers Caring for Family Members (or Friends) with Cancer
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Aims: Older people may not receive appropriate palliative care, and family members provide essential end of life support at home. Research has focused largely on younger adults, with a gap in understanding of the needs of older people with cancer and their family caregivers. The aims of this longitudinal qualitative study were to explore the needs of family caregivers, develop a model of family caregiving, and identify opportunities to develop support strategies.

Methods: 25 pairs of participants (person with cancer+nominated family caregiver) aged ≥65 years were recruited via community palliative care teams (mean age 77.8 years, range 68-91 years). 17 care recipients were men and 8 women. 18 caregivers were women and 7 men. Most caregivers (21/25) were spouses. We conducted 55 in-depth interviews with 25 people with cancer and their main family caregiver/friend. Each pair of participants was interviewed up to 3 times over 6 months. 19/25 pairs of participants took part in at least 2 interviews. Structured questionnaires were completed to evaluate service use. Interview transcripts were coded line-by-line and events and actions classified into categories and sub-categories. Relationships between categories and their properties were established to provide the basis for a model of family caregiving. Service use data were analysed descriptively.

Results: The emerging model of family caregiving suggests that caregivers find themselves at the centre of many converging lines of responsibility. Daily life is strictly scheduled according to a timetable of health-related activities and focused on a narrow physical and metaphysical space. The intensity of this experience can be hard to contain.

Conclusions: Supportive interventions, including community initiatives, should provide relief from the work of containing the full range and number of caregiving demands, and the tendency towards an increasingly tightly boundaried day-to-day life. Funded by Dimbleby Cancer Care.
Abstract number: P400
Abstract type: Poster

Relationship between Perceived Personal Competence and Main Caregivers Overload of Dying Patients

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Background: The care of a loved one at the end of life is a difficult and complex task. Early detection of wear or caregiver overload when it loses its capacity to care, is one of the key elements to promote the adaptation of the carer. In a situation of great emotional impact, it is assumed that perceived personal competence (PPC) is a general and unspecific belief about their own capabilities might be a good predictor of the capacity of care and resistance of main caregiver.

Aim: Analyze the role of PPC as modulator of caregivers overload (CO) of dying patients attended in a palliative care unit.

Methods: 36 main caregivers of dying patients admitted at the Hospice Care Unit participated voluntarily in this study giving their written consent. Carers through a semi structured interview answered the following questionnaires: Zarit reduced scale, and scale of perceived personal competence (Wallston scale) as well as some sociodemographic variables.

Results: 61.1% of family caregivers have overload. We do not observed differences in CO according to sex or degree of kinship of the main caregiver. We observed negative correlations between PPC and CO, both in overall score and in each of the three sub-scales of Zarit scale: overload, self-management and loss of roles. Less PPC is related to CO and with their age.

Conclusions: These results show that PPC could predict the strength and ability of caregivers in the care of patients at the end of life, ie overload caregivers. In this sense, the main caregivers who have a higher PPC are less likely to have overloaded. Also, it seems that the age of caregivers is a key element in the overload, being of older carers who are more likely to suffer it. Palliative care should be aware of these issues and improve the carers’ resources that have a low perceived competence to prevent overload.

Abstract number: P401
Abstract type: Poster

Home Hospice Care: Does it Contribute to the Mourning Experience of Bereaved Families?

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Aims: One principle of hospice care is to support family members after the patient’s death. The study goal was to compare the mourning experience of relatives of home-hospice patients with that of relatives of patients who received care from a different service.

Methods: Face-to-face interviews were conducted with a representative sample of 193 family caregivers of patients who died of cancer, about 6 months after their death, using a validated 22-item questionnaire - Revised Grief Experience Inventory (RGEI) - and a questionnaire about bereavement services and support given to the family.

Results: The average age of the family members was 53; 59% were women; 42% spouses; 43% sons or daughters; 15% other family members. A fifth of the patients received care from home hospice, the rest received care from other services. Among those whose loved ones had been in a home-hospice setting, the majority had been in contact with the care team after the patient’s death, compared to only a half of the relatives of patients cared for by other community services and a minority of hospital patients.

A factor analysis of the RGEI revealed 3 dimensions: loss of meaning/significance in life; hyperactivity/angry outbursts; introversion/depression. In all, the grief response was greater among the spouses than among the children, among people with lower education, and among relatives of younger patients.

Hospice care had an independent effect on a reduced sense of grief in the hyperactivity and depression dimensions in a multivariate analysis controlling for kinship with the patient, the caregiver’s education and the patient’s age.

Conclusion: Home hospice care has a positive effect on the mourning experience of family members whose relative died of cancer and on their ability to cope.

Abstract number: P402
Abstract type: Poster

Using the Carer Support Needs Assessment Tool (CSNAT) in Practice: What Have We Learned?

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Aims: To identify the impact of using a structured tool for carer assessment on how specialist palliative care services provide support for carers at home.

Current UK policy recognises the important contribution of family carers in end-of-life care, recommending that their needs should be assessed to support them in their caring role. However, there is little evidence on how this should be achieved in practice. We have developed an evidence-based Carer Support Needs Assessment Tool (CSNAT) for end-of-life home care practice to facilitate carer assessment and support; a 14-item tool completed by carers to identify and prioritise their support needs for discussion with hospice home care (HHC) staff.

Sample: Two UK HHC services differing in size, model of service delivery and timing of patient referral to service. 23 staff participated: service managers, qualified nurses and nurse specialists and care assistants.

Methods: Focus groups pre and post implementation and reflective diaries provided staff experiences of CSNAT use. Thematic analysis using framework approach.

Results: Study on-going in one setting. Benefits of CSNAT use for HHC include demonstrating service interest in carer support and enabling visibility of carer needs. Challenges related to integration of a structured tool into existing practice, including appropriate timing for introduction of the CSNAT to carers, whether it was felt to enhance practice and tackling workload implications of a separate assessment for carers. Contrasts with previous practice of carer assessment will be discussed in more detail.

Conclusion: The benefits and challenges of integrating a structured comprehensive assessment of carer support needs will inform development of a training guide for practitioners using the CSNAT. Insights from this study have important implications for service providers delivering support to carers and for the development of policy on carer assessment.

Abstract number: P403
Abstract type: Poster

How to Be a ‘Good Carer’? Perspectives on Older Adults’ End of Life Care from Family Carers and Health and Social Care Professionals

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Aims: The concept and practice of the ‘good patient’ role is well established and has been supplemented more recently with recognition of the ‘expert patient’. Expectations for family carers’ roles have rarely been considered. This paper discusses family carers’ perspectives on the most appropriate and effective ways to support care recipients and liaise with health professionals, contrasting this with health and social care professionals’ expectations.

Methods: In-depth qualitative interviews in England, focused on transitions in the last year of life for older adults with heart failure, Chronic Obstructive Pulmonary Disease (COPD), breast cancer, colorectal cancer, lung cancer or following a stroke with:

- 120 informal carers of people who died in the last 3-14 months aged 66-98 years
- 40 health and social care professionals or commissioners

Results: Two main patterns emerged for family carers’ liaison with health services to promote older adults’ wellbeing. Many spousal carers of older adults adopted a passive accepting stance similar to the ‘good patient’ role, preferring to put confidence in health professionals’ decision-making, rather than becoming concerned with complex details or risking being a “bother.” Most adult children caregivers and younger spousal carers acted as advocate and agent, researching details, asking questions about likely options and outcomes, and challenging health professionals where necessary. The paper will contrast carers’ approaches with health and social care professionals’ expectations about how family carers should most effectively engage with them, to facilitate good end of life care.

Conclusions: Carers from different age groups may take on different roles when interacting with authority. This paper will draw conclusions about satisfaction and perceived outcomes of different family carer approaches, and how well their understanding of their role accords with the views of health and social care professionals.

Abstract number: P404
Abstract type: Poster

Palliative Sedation: From the Family Perspective

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Introduction: Palliative Sedation (PS) is the treatment option in case of refractory symptoms at the end of life. PS has triggered many discussions and controversial reactions. The European Association of Palliative Care has now published guidelines about PS. Several studies have focused on the experience of nurses and doctors during a PS procedure. However, only 2 studies (Japan
and Netherlands) showed interest in analyzing the family perspective.

**Method:** Retrospective study, approved by the local ethic committee, including the closest family member of patients deceased under PS at our institution from Oct 2009 to Sept 2010. The anonymous questionnaire included satisfaction about information concerning PS, perception of the procedure and personal experience.

**Results:** 24 patients died under PS during the observation period (less than 10% of all deaths). Seven cases were excluded from the beginning due to absence (n=2) or proof that the family member was informed about PS (n=5). 59% answered the questionnaire (10/17). Nine relatives out of ten were sufficiently informed about PS. 80% have agreed to the necessity to initiate PS and 70% evaluated the chosen moment as adequate. All the relatives have noticed an important improvement of the refractory symptom with a mean reduction of the estimated suffering of 6.25 points on a visual analogue scale (1 to 10). The individual suffering of the family member was very personal without a link to the intensity of the patients’ symptoms or the attention the medical staff brought to the sedated patient.

**Discussion:** PS should be performed in the best possible way for the patient and his family. The information given to the patient and his family is crucial to the good clinical practice of the procedure. Under these circumstances PS reduces efficiently a refractory symptom. However, the results of this study are limited due to the very few participants and the absence of analysis of the non-responders. No financial conflicts.

**Abstract number:** P405
**Abstract type:** Poster

**Hospitalization of Advanced Cancer Patients: A Systematic Review**

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**Introduction:** Palliative care focuses on the quality of life. Hospitalization of advanced cancer patients could be a contrast to the quality of life.

**Aims:** The aim of the study was to describe the current state of knowledge on hospitalization of advanced cancer patients.

**Methods:** From January 2011 to February 2011 a systematic review was conducted in databases: Pubmed, Embase, Cinahl and Psychinfo. Original research studies had to describe information on the duration and frequency of hospitalizations, reasons for admission, influencing factors and the decision making process.

**Results:** A total of 204 articles were identified published from 2000 to 2011. The final selection consisted of 27 articles. Due to heterogeneity (study population and methodology) meta-analysis was not possible.

Hospitalization duration and frequency increased during the last three months of life, excessively increasing during the last week to death.

Hospital admissions were caused by symptoms, illness related-, treatment related and psychosocial factors. Influencing factors on hospitalization were demographic-, patient related, caregiver related, and professional care related. Most hospitalizations in palliative care were acute, needing acute interventions. No decision making process on hospitalizations was described in the literature.

**Conclusion:** Hospitalization in palliative care is a problem during the last three months of life, specifically towards death. Causes of hospitalization were mostly physical, due to symptoms, and illness- and treatment related. These emergency hospitalizations can decrease the quality of life of patients and family caregivers. Prevention of emergency admissions should focus on patient-, family- and healthcare related factors. This can ameliorate the quality of palliative care in the continuum of cancer care.

**Abstract number:** P406
**Abstract type:** Poster

**The Impact of Family Conferences in Palliative Medicine**

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**Introduction:** Our acute care unit has 800 admissions a year; over half have a family conference (FC). The FC is a formal scheduled meeting, patient approved, attended by physician/Social Worker (MSW), Patient spokesperson (SP), and family. To evaluate the FC a study was designed to:
1) identify patient and attendee characteristics
2) evaluate family information needs
3) assess spokesperson distress.

**Methods:** Consecutive eligible cancer patients were recruited; a 19-item survey of SP information needs was done pre- and post-FC. SP completed a Distress Thermometer (DT)NCCN pre- and post-FC.

**Results:** 80 FC eligible. Demographics Median age 63; 55% female; 53% married; 30% African-American. Transition of care was the reason for 85% of FC. 54% had Health Care Power of Attorney; 26% were full code. FC Process Location:
bedside 60%, meeting room 40%. Median duration was 45 min. 

Abstract number: P407
Abstract type: Poster

Cultural Differences Affecting Euthanasia Practice in Belgium: One Law but Different Attitudes and Practices in Flanders and Wallonia

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Since 2002, Belgium has had a national law legalising euthanasia. The law prescribes several substantive due care requirements and two procedural due care requirements, i.e., consultation with an independent physician and reporting of euthanasia to a Federal Control Committee. A large discrepancy in reporting rates between the Dutch-speaking (Flanders) and the French-speaking (Wallonia) parts of Belgium has led to speculation about cultural differences affecting the practice of euthanasia in both regions.

Using Belgian data from the European Values Study conducted among a representative sample of the general public and data from a large-scale mail questionnaire survey on euthanasia of 480 physicians from Flanders and 305 from Wallonia, this study presents empirical evidence of differences between both regions in attitudes towards and practice of euthanasia.

Acceptance of euthanasia by the general population was found to be slightly higher in Flanders than in Wallonia. Compared with their Flemish counterparts, Walloon physicians held more negative attitudes towards performing euthanasia and towards the reporting obligation, less often labeled hypothetical cases correctly as euthanasia, and less often defined a case of euthanasia having to be reported. A higher proportion of Flemish physicians had received a euthanasia request since the introduction of the law. Requests were more often granted in Flanders than in Wallonia (51% vs 38%), and performed euthanasia cases were more often reported (73% vs 58%).

The study points out some significant differences between Flanders and Wallonia in practice, knowledge and attitudes regarding euthanasia and its legal requirements which are likely to explain the discrepancy between Wallonia and Flanders in the number of euthanasia cases reported. Cultural factors seem to play an important role in the practice of (legal) euthanasia and the extent to which legal safeguards are followed.

Abstract number: P408
Abstract type: Poster

New Housing Models for People with Dementia towards the End-of-Life

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Background: New housing models based on small units are supposed to offer high quality care for people with dementia. A broad variety of different services has been developed in the last years all over Europe. Research on end-of-life care in these settings is in its infancy and has mostly maintained a national scope although common challenges are faced in this area.

Aim & method: To gain an overview of state of knowledge and practice in this area at an international level and to develop a research agenda an Exploratory Workshop is funded by the European Science Foundation (Exploratory Workshop Scheme) to take place in Vienna in December 2011. 18 experts from six European countries with different academic disciplines and backgrounds are sharing knowledge of research available in the overlapping fields of end-of-life care and new housing models. The aim is to develop a research agenda and common research ventures.

Results: Preparation work has shown that end-of-life care in these settings still needs more attention, with implications of this challenge being elaborated on an interdisciplinary ground. At an international level it is inevitable to clear terms and definitions in this diverse field to find a set of convenient working definitions. Of similar importance it is to map different types of housing models to find a set of convenient working definitions. Of similar importance it is to map different types of housing models to understand the various developments and traditions in the different countries with reference to national frameworks and policies concerning dementia care, housing and EoIC.

Conclusion: Key aspects of the research agenda will be developed at the Workshop and presented at the Congress to offer options for future research activities and collaboration.
Stress and Depression in Health Care Professionals Evoked by Dying Palliative Care Patients. A Prospective Cross-sectional Study

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Aims: Death of patients with advanced cancer may evoke specific stress reactions in their professional caregivers. We monitored stress intensity and signs of depression in hospital nurses and physicians and studied their association with specific characteristics of deaths occurring on their wards.

Methods: Sixty nine nurses and twenty physicians taking care of hospitalized cancer patients at a large municipal cancer centre participated in the study. They were asked to fill out validated questionnaires for health care related stress (GHQ) and depression (HADS-D) and a costume made questionnaire which aimed to record subjective estimation of personal bonding to patients in general. Number of deaths in the week preceding the completion of questionnaires and intensity of previous work with the deceased patients was recorded for each health care professional. All statistical analyses were performed on SPSS 19.0.

Results: A total of 270 questionnaires were completed. Intensity of personal bonding to patients correlated weakly but was associated significantly with GHQ (p= 0.002; r=0.22). Similar results were obtained when the association of number of deaths and GHO was analyzed (p= 0.04; r=0.12). Self-assessment of personal bonding to patients in general correlated weakly but significantly and negatively with HADS-D (p= 0.01; r =-0.28). A strong and significant negative correlation was observed between GHO and HADS-D (p=0.001; r= -0.670). No association was found between intensity of previous contact with patients and any of the variables tested.

Conclusion: Our data show that levels of depression and stress are only weakly influenced by number of deaths occurring or by the intensity of relationship with the patients. Caregivers with a self-assessment of high personal bonding to patients have significantly less signs of depression. Similarly, caregivers with higher work related stress levels show highly significantly lower depression levels.

Abstract number: P409
Abstract type: Poster

Variations in ‘Out of Hours’ End of Life Care Service Provision across Primary Care Organisations in England and Scotland: Patient Identification, Access to Care Plans and Co-ordination of Care

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Few studies have recognised the complex service web which end of life (EoL) patients and families rely on for emergency and urgent care outside ‘normal’ working hours. We have explored EoL out of hours (OoH) care variations across Primary Care Organisations (PCOs) in England and Scotland, and providers and commissioners’ views of service provision. We focus here on emerging findings on patient identification, access to care planning, and care co-ordination.

Methods: Semi-structured telephone interviews with informants knowledgeable about commissioning and/or provision of EoL OoH care in sample of PCOs.

Results: 114 PCOs were sampled. 45% participated. Participating PCOs had larger populations than all PCOs. Two thirds had mechanisms for identification of EoL patients in GP practices which were not restricted by diagnosis, were used by most GP practices, and where the information was regularly updated. Almost all PCOs (91%) had systems for GPs to inform OoH services about EoL patients: 56% relied on fax or email, and 35% used electronic systems in at least some practices: ambulance services could only access this information in one in five PCOs. GPs and OoH providers shared electronic systems in 18% of PCOs. Incompatible IT in different parts of the health system caused concern. Difficulties were reported in integrating EoL OoH care across complex networks involving diverse services and organisations: improvements in co-ordination and in communications between health professionals were a priority.

Conclusion: Although mechanisms to identify proactively EoL patients in general practice were widespread, better system-wide access to care plans and improved service co-ordination is needed.

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Abstract number: P411
Abstract type: Poster

Madeira Island: Implementing Palliative Care Population Based
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Introduction: In Madeira Island, an autonomous region from Portugal, there is no palliative care. There is a Central Hospital and Primary Care health professionals along the island. We intended to show to the decision makers the need for palliative care based on the population data and help inform decisions about how healthcare should be organized to support those in need of end-of-life care.

Methods: The Regional Health Statistical department database was searched for the total number of deaths in the years of 2007, 2008, 2009. From these deaths we went to look the causes and places of death and for how many visited the emergency department in the last two weeks of life.

Results: In the years of 2007, 2008 and 2009 there were a total of 2562, 2595 and 2642 deaths. There were three main causes of death that we assembled in cardiovascular (27,32%; 28,01; 26,68%), cancer (19,24%; 20,73%; 18,7%) and respiratory (16,74%; 16,53%; 18,73%) for the same years. From all of these deaths there are some missing data for the year of 2007 regarding the place of death. In the year of 2008 and 2009 the inpatient hospital deaths were of 70,02 and 68,09% and home deaths were responsible for 17,96% and 18,62%. From these deaths 15,26 and 16,08% happen to occur in the emergency department. In the last two weeks of life visited the emergency department 51,75%, 54,83% and 55,98% (with or without admission) of patients.

Conclusion: This study shows that Madeira Island has high hospital mortality. Prior to death more than 50% of patients had visited the emergency. Such visits made near the end of life are considered a indicator of poor quality of cancer care, though we didn’t looked for how many were cancer patients, nevertheless many visits near the end of life may be avoidable with organized palliative care. A strategy to help decision makers about palliative care organization is suggested.

(The funding of these study was strictly from researchers)

Abstract number: P412
Abstract type: Poster

Proactive Palliative Care: Nurses’ Perspectives
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Background: Early identification of pain and other (physical, psychosocial and spiritual) problems is an important aspect of palliative care, as emphasized in the definition of the World Health Organization. This suggest a proactive role of healthcare professionals. Although nurses have an important role in palliative care, little is known of nurses’ perceptions of proactive palliative care.

Objectives: To explore nurses’ perceptions and experiences regarding proactively identification of problems and needs of patient in palliative care.

Methods: Qualitative study using 2 focus group interviews with 16 nurses working in palliative care (4 hospital nurses, 12 community nurses). Interviews were fully transcribed and analyzed using the interview topics.

Results: Although nurses find it difficult to define proactive palliative care, they all underline the importance of involvement in palliative care in an early stage, for instance shortly after diagnoses of incurable disease. Anticipation of possible future problems, advice and information about end of life care and palliative care facilities, assessment of patients’ wishes regarding end of life care and palliative care support patients’ management in palliative care.

Conclusions: Nurses’ involvement in proactive palliative care support patients’ management in palliative care.

Abstract number: P413
Abstract type: Poster

Improvement Areas in Palliative Care in Madrid (Spain) from the Point of View of Palliative Care Professionals
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The city of Madrid and its metropolitan area has a population over 6 million inhabitants. Promoted by the regional
coordinating palliative care, and as the beginning of a larger qualitative study that seeks to define the concept of complexity in palliative medicine, the research team intends to know the current status of development of palliative care in this Spanish region, from the point of view of professionals working in palliative care.

**Method:** Between March 2010 and January 2011 were conducted open interviews with the responsible of palliative care teams, group interviews with palliative care teams, and a focus group of professionals from charity units. Each interview began with an open question about complexity in palliative care. For the final report was made a working group with the palliative care professionals from Madrid.

**Results:** As general aspects of palliative care situation in Madrid highlighted the remarkable but irregular development, patient late referral, advanced cancer patients profile, lack of definition when to intervene with organ failure patients, and not cancer pediatric patient profile. The areas of improvement seem to be the organization of health and social resources, the improvement of psychosocial resources, and training not palliative care professionals in palliative medicine.

From this initial approach the complexity seems to be related to the relation between the needs of the target population, the resources availability, and the training and knowledge on palliative care.

**Abstract number:** P414

**Abstract type:** Poster

**An Evaluation of Pharmacist Interventions as Part of the Clinical Palliative Care Team in a Hospice**

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**Aim:** We aimed to quantify the type and impact of pharmacist interventions documented over a 12 month period. The positive impact of pharmacist interventions in various healthcare settings is well documented as improving patient safety and preventing medication related errors. This complies with the National Patient Safety Agency goals for improving patient outcomes. There is little evidence for this in the palliative care setting; this study attempts to evaluate if the benefits seen elsewhere can be applied to palliative care.

**Method:** Pharmacists working in the hospice were asked to record their interventions on to a computer which allowed the confidential capture of patient specific data. Data was attached to individual patient records. Interventions were recorded in the category “Pharmacist intervention” which was subdivided by timing of intervention e.g. admission check, advice requested, during ward round, discharge prescription check. The complete note records for the period 01.10.10 to 30.09.11 were read and analysed.

Interventions were collated by timing of intervention and then qualitatively assessed for clinical importance and clinical risk using the NPSA Risk Matrix assessment guide.

**Results:** Data collation is ongoing but the preliminary analysis suggests the majority of interventions are made during admission checks and at discharge. Potential consequences of not making the interventions ranked from “negligible” to “moderate” but none were classed as “catastrophic” although the majority calculated as “moderate” or “high” clinical risk. Complete results will be presented.

**Conclusion:** This evaluation demonstrates that pharmacist interventions prevent “moderate” and “high” risk medication related errors in the palliative care setting, particularly on admission and during the discharge process. This supports data already published and further work is needed to demonstrate the cost benefit that a pharmacist could provide as part of the palliative care team.

**Abstract number:** P415

**Abstract type:** Poster

**The Conceptualisations of Patients’ Dignity from Professionals’ Perspectives: A Qualitative Synthesis Study**

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**Background:** Currently dignity is of considerable concern in western health care systems, especially in palliative care. As dignity is viewed as a nebulous concept, several studies exploring conceptualisations of dignity have been conducted in different clinical settings. Those showed that dignity is embedded in human interaction and that the interaction between professionals and patients has a profound influence on patients’ sense of dignity. However, no systematic review was found in this area. Consequently a synthesis of relevant qualitative studies was conducted to explore health care professionals’ perspectives on patients’ dignity.

**Aim:** To obtain an in depth understanding of patients’ dignity as conceptualised in western health care systems from the health care professionals’ perspectives.

**Methods:** Eight medical databases were searched. Of 2,211 articles screened, nine qualitative studies were included and critically examined using the appraisal tool Consolidated Criteria for Reporting Qualitative Research. Meta-ethnography was employed to synthesise findings from these studies and both reciprocal translation and line-of-argument syntheses were conducted.
Results: Participants recruited to these studies looked after general medical, elderly and critically ill patients. Three themes relating to patients’ dignity were identified: ‘illness and aging’, ‘care delivery’ and ‘barriers to providing dignified care’. Among these themes, three subthemes were mentioned only by those who looked after critically ill patients: ‘existential distress’, ‘dead body as a person’ and ‘opportunity of farewell’.

Conclusion: From professionals’ perspectives, patients’ dignity is seen as an inherently worthy quality of human beings. Health professionals’ education regarding patients’ dignity on the aspects of existential needs and dying care is needed for those who look after general medical and elderly patients.

Abstract number: P416
Abstract type: Poster

Acceptance and Effectiveness of Specialized Home Palliative Care Teams in Children and Adults
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Objective: Since 2007, German patients with severe, advanced life-limiting diseases and complex needs are eligible for specialized home palliative care (SHPC). SHPC teams were established as a new facility in the German health care system. To assess the acceptance and effectiveness of this new service we are currently conducting a study on two of the first SHPC teams in Germany, the adult and the pediatric SHPC team at the Munich University hospital. An interim analysis after the inclusion of about 50% of projected patients is presented.

Methods: All consecutive patients treated by the two SHPC teams are eligible for the prospective, non-randomized study. Exclusion criteria are patient or parent refusal, inappropriate language knowledge, and severe cognitive deficits. Two questionnaires were developed to assess the patient and the spouse/parent situation before and after the care by the SHPC team. The main topics were pain and symptom control, quality of life (QoL) in patients and relatives and the burden of care for the relatives.

Results: 41 adult (median age 69 yr, 61% male, 81% oncologic diseases) and 11 pediatric patients (median age 5 yr, 55% male, 82% non-oncologic diseases) were included so far. In 17/41 adult and 9/11 pediatric patients only the relatives could be interviewed. The median interval between the first and second interview was 2.7 weeks in adults and 6.3 weeks in children. At the first interview 58% of adult patients suffered from severe pain, but none did at the second time point. The QoL in adult patients and spouses increased (MQOL 69 to 101; QOLLTI-F 95 to 115) as it did in parents (QOLLTI-F 92 to 116), and the burden of care decreased (HPS in spouses 12 to 7, in parents 17 to 7).

Conclusions: The preliminary results suggest that SHPC teams can provide effective help to patients and families, improve the QoL in patients and relatives, and lower the burden of palliative home care for the relatives of severely ill adults or children.

Abstract number: P417
Abstract type: Poster

Patients Presenting with Metastatic Cancer of Unknown Primary (CUP): The Importance of Palliative Medicine Independent of the Final Diagnosis
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Background: In England and Wales recent national guidance highlights inequity regarding care, and research, for those presenting with metastatic Cancer of Unknown Primary (CUP) compared to site-specific cancer.

Aim and methods: Within a mixed methods research study to evaluate the development of a hospital team and pathway for patients presenting with metastatic CUP, we undertook a retrospective cross-sectional analysis of patient data before and during implementation. Detailed here is analysis of patients with CUP presenting to a hospital (375,000 catchment population) over two six-month periods.

Results: A total of 88 patients were identified as presenting with metastatic CUP (median age 75 years, range 44-98 years old). Of these 63 patients (71.5%) were referred for Specialist Palliative Care (SPC) either during the investigatory period or as their definitive treatment. A further 13 patients (14.7%) were referred for SPC at some point during their illness. A primary tumour was identified in 44 patients (50%); the overall referral rate to SPC (86.3%) was the same in this group of patients as to those with a final diagnosis of metastatic CUP. Of the 88 patients, 39 (44.3%) were referred for consideration of Tumour Directed Treatment (TDT) and 23 (26.1%) completed the planned treatment. Median time from presentation to death was 40 days.

Conclusion: The majority of patients presenting with metastatic CUP, independent of whether a primary site is later identified, require Specialist Palliative Care. Only a minority will complete TDT. This highlights the importance of early palliative medicine involvement to ensure that
management is patient and symptom focused. Invasive investigations were only undertaken if TDT is appropriate and acceptable to the patient.

**Funding:** Macmillan Cancer Support

**Abstract number:** P418

**Abstract type:** Poster

**Transitions between Care Settings: Perspectives on End of Life Care for Older People in England**

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**Aims:** Transitions between care settings occur frequently at the end of life, representing a significant demand on health services. This paper explores the experiences and consequences of end of life transitions in England, for older patients and their families.

**Methods:** Mixed methods study of transitions in the last year of life for older adults with heart failure, stroke, chronic obstructive pulmonary disease, lung, breast and colorectal cancers.

- 30 patients aged 69-93 years and in the last year of life - in-depth interviews
- 120 informal carers of people who died in the last 3-14 months aged 66-98 years - in-depth interviews and questionnaire survey
- 40 health and social care professionals or commissioners - vignette based interviews

**Results:** Most transitions into hospital were unplanned, emergency events, whereas moves home or to other institutions were often influenced by patients and their families. Admissions to hospice were generally very late in the illness, often in the final hours of life. Pain was reported as tolerable in all settings, though carers perceived that patients sometimes under-reported pain to avoid escalating care and prompting a transition. With the exception of multiple hospital admissions for the same problem, carers tended to report that transitions were appropriate, even when their narrative suggested that more community support may have prevented the move. However, a lack of information and communication for carers, inadequacies in information transfer across settings and difficulty negotiating complex systems were common.

**Conclusions:** Much good care is being delivered in certain settings, but transitions are a source of distress and may be associated with a loss of carer continuity and influence. Better communication, forward planning, simplified funding processes and support for families to identify suitable settings for their relative’s care, would all help to improve deficiencies in end of life care.

**Abstract number:** P419

**Abstract type:** Poster

**The Effects of Palliative Care Consultations on Hospital Costs and Family Satisfaction**

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**Background:** There is a growing interest for palliative care consultation teams in hospitals. Research has indicated that such consultation is able to improve care for patients with advanced diseases, whereas others have pointed to potential cost savings. European figures are largely absent. This study examines the effect of a palliative care team both on hospital costs and family satisfaction of patients with advanced cancer.

**Methods:** A retrospective cohort study was performed in a Dutch hospital in the period June 2010 until May 2011. Advanced cancer patients with breast-, colorectal-, or pancreas cancer receiving a palliative care consult were matched by diagnosis with patients receiving usual care. Hospital costs in the last 6 weeks of life were compared using administrative hospital data. In addition, a cross-sectional survey was administered to family members of these two groups of patients to measure satisfaction with care, the FAMCARE scale.

**Results:** Fifty patients that received a palliative care consult in this period were matched to fifty usual care patients. The palliative care patients had a net savings of 39 euro per treatment day compared to usual care patients (P=0.02; t-test). In total 19 family members within both groups responded to the survey reporting higher satisfaction in the palliative care consultation group (P=0.26; t-test). Two items of the FAMCARE scale were significantly different, namely item 4 describing the information given about side effects (P=0.03; t-test) and item 16 describing the information given about how to manage the patient’s pain (P=0.02; t-test).

**Conclusions:** Palliative care consulting in a Dutch general hospital significantly reduced hospital costs and increased family satisfaction at the end of life. Further multicenter research is indicated.
Abstract number: P420
Abstract type: Poster

Improving Access to Palliative Care Services: Rapid Consultation in a Hospital Emergency (Accident / Casualty) Department

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Background: In the US, our Palliative Care program is unique in its early intervention in the Emergency Department (ED) (also known as Casualty or A&E). Our medical school also requires all residents (house staff) to do a 2-week rotation on the palliative care service.

Aims: Our goals for this study were to
1) describe palliative care involvement in the ED at our hospital;
2) describe the typical reasons for PC involvement; and
3) describe what happened to patients following initial consultation.

Methods: We analyzed the information recorded for palliative care consultations from the years 2006 - 2011 that occurred in the ED. For the years 2008-2011 we matched the consult data to hospital billing and administrative databases for the ED visit and/or eventual hospitalization, to determine additional characteristics about the patients and their hospital care.

Results: Since 2006, 429 patients received a palliative care consultation during an ED visit. This increased from 36 in 2006 to more than 90 in each of the past two years. Reasons for consultation included pain (52%), other symptoms (54%), and goals of care (54%); 17% were solely for pain, 11% were solely for other symptoms, and 21% were solely for goals of care. Hospital data were available for 252 cases seen since July 2008. Six died in the ED, 31 were released from the ED (most of whom were referred to or enrolled in hospice at that time), twelve were held in the hospital as “observation” cases, and 203 (81%) were admitted. Fifty-one (25%) of those hospitalizations ended in death and another 25% ended in discharge to hospice. 162 (80%) were admitted to the designated Palliative Care Unit, for an average of 3.9 days, almost all directly from the ED.

Conclusions: The experiences of our program may have lessons for others worldwide regarding establishing a relationship with ED providers and assisting them as needed. The ED providers are seeking help with determining the best pathway for a given patient.

Abstract number: P421
Abstract type: Poster

How Many Palliative Patients Are there? Making the Case for a New Hospital Palliative Care Consultation Team (PCCT)

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Background: In making the case for a hospital PCCT, we need to determine the number of patients that could benefit from such a service, yet identifying these patients in acute care remains challenging. To build support for a new PCCT, we piloted a method of identifying potential PC patients in an acute care hospital.

Methods: In a 2 week cross-sectional study, attending physicians of medical inpatients were asked 3 questions to identify patients who could benefit from PCCT. The patients’ medical charts were then reviewed using “risk of mortality indicators” (RMI) drawn from the literature to estimate a life-expectancy of ≤ 12 months for cancer and non-cancer diseases.

Results: Six physicians were questioned on 85 patients. Question 1: “Would you consult PC for this patient if the service were available?”, identified 22/85 (26%) but surprisingly failed to identify 15 out of the 30 patients who met the RMI criteria in chart review (life-expectancy estimated at ≤ 12 months). Question 2: “Would you be surprised if this person was still alive in 12 months?” identified 33/85 (39%). Question 2 failed to identify only 20% of those who met the RMI criteria. Moreover, it identified only 7 patients with an estimated life-expectancy > 12 months. Question 3: “Does this patient have a progressive incurable illness and symptoms to control?” identified 62/85 (72.9%), and included all 30 patients who met the RMI.

Conclusion: The study was successful in building support for our new PCCT. Question 1 in itself was sufficient for making the case, but underestimated the needs, as highlighted by Questions 2 and 3. Question 2 seems to give a good middle ground, missing only 20% of patients with an estimated life-expectancy > 1 year according to the RMI. The developed RMI were meant to give an objective evaluation of the palliative care needs based on life-expectancy, but require considerable more research to be clinically useful.

Abstract number: P422
Abstract type: Poster

Getting to Palliative Care Is a Still Painful Step

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There are factors that play a crucial role in the transition from active treatment to palliative care: the clinical complexity in determining with certainty the prognosis of the patient and the practitioner’s ability to identify the most appropriate time to discontinue the active treatment. The latency period in the transition from active treatment to palliative care seems to be placed in the departments of oncology, surgical oncology and medicine.

**Objectives:** Identify and understand which meaning doctors and nurses assign to the procedures and the barriers that determine the latency period in the transition from active to palliative care within the Operating Units of the Oncology Centre of Piedmont and Aosta Valley. Understand and analyze the field of knowledge and the behaviors of staff physicians who deal with end-stage cancer patients.

**Tools and methods:** Qualitative study carried out at two levels (target 1: professionals; target 2: patients and caregivers).

Target 1: nurses and physicians working in Oncological Medicine and Oncological Surgery Units of 4 hospitals in Piedmont.

Target 2: patients and caregivers of 4 hospices in Piedmont.

The instrument used at both levels is the in-depth interview. Data will be processed according to the indicators of good practice of qualitative research, with traceability of interpretations. We will use the software N-Vivo to analyze the narratives and detect the emerging issues.

**Expected outcomes:** To understand which are the obstacles that determine a latency period in the transition from active to palliative care.

Explore and describe the position taken by practitioners in hospital units.

Identify the barriers to the reporting of terminally ill patients.

Identify possible areas for improvement in order to reduce the waiting days in the transition to palliative care.

The study is still ongoing and results will be available from February 2012.

**Funding:** Oncological Network of Piedmont and Aosta Valley

**Abstract number:** P423

**Abstract type:** Poster

**Primary Home Care for Palliative and Terminal Patients near Lisboa: Nursing Practice and Hospital Palliative Care Team Support**

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In Portugal, a great number of palliative and terminal patients wish to stay and die at home, surrounded by their relatives and significant objects. These patients are commonly cared by professionals, namely nurses, from primary health care system, developing an integrated work with some palliative care units in hospitals. What interventions have those nurses in their everyday practices? How can the relationship and support between these nurses and the hospital palliative care team be optimized?

**Aims:** To identify the interventions conducted by nurses from primary care when caring for palliative and terminal patients at home; to analyze these professionals view about those interventions; to identify the barriers in relation to primary care nursing practice in end-of-life care; to analyze the support given by hospital palliative care teams to those nurses who care for palliative and terminal patients at home.

**Methods:** Qualitative, exploratory and descriptive study. Sample compounded by nurses who work in primary care settings nearby the Portuguese capital (Lisboa) and who provide home care for palliative and terminal patients. Participants are being recruited through intentional sampling. Five in-depth interviews have already been conducted; data collection will be held until theoretical saturation. QSR NVivo 9 is used for content analyzes.

**Results:** Preliminary results (five participants) indicate that the most relevant interventions conducted by these nurses are symptom control and management of complex situations related to family issues and expectations management; these professionals also refer a lack of education in palliative care in order to answer to all the patients and their relatives’ needs. The major barriers are related to organizational aspects. Hospital palliative care teams are seen as a valuable resource however more effective strategies are felt to be needed in order to improve the communication between the hospital and the primary care institution.

**Abstract number:** P424

**Abstract type:** Poster

**Factors Influencing Quality of Hospice Care Perceptions among Bereaved Caregivers after Participation in a Randomized Controlled Trial**


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**Aims:** To identify the factors influencing quality of hospice care perceptions among bereaved caregivers after participation in a randomized controlled trial.
completing their participation in a randomized controlled trial examining the efficacy of parenteral hydration (PH) in cancer hospice patients.

**Methods:** Bereaved caregivers were interviewed cross-sectionally within 3-23 months after their loved one’s death to assess their: quality of hospice care perceptions (Family Evaluation of Hospice Care); attitudes and beliefs regarding PH; and past/present grief levels and grief reaction group (Texas Revised Inventory of Grief). Bivariate analyses were conducted to identify factors associated with quality of care perceptions.

**Results:** Seventy-six interviews with bereaved caregivers previously enrolled in the trial were completed (78% response rate). The majority (84%) of caregivers reported that the quality of hospice care received was “very good” or “excellent”. Factors influencing higher levels of satisfaction with care were: agreeing that PH was beneficial for their loved ones (P = 0.004) and greater number of days of trial enrollment (P = .015). No other significant associations were identified by past/present grief levels, grief reaction group, or other demographic and clinical variables (i.e., age, ethnicity, education length of hospice service, group assignment).

**Conclusion:** Our findings suggest that clinical research in hospice populations is feasible/ plausible and may result in improved levels of satisfaction with standard care perhaps due to the additional level of care/attention from the clinical research staff.

**Abstract number:** P425
**Abstract type:** Poster

**Care and Transfers in the Last three Months of Life of Older People: Changes over a Decade**

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**Context:** With the aging of the population, not only do people live longer, they also live longer with chronic diseases and usually with multiple medical problems predominantly in the last year of life. Consequently there is an increased need of care and in particular for more complex care closer to death.

**Objectives:** To study the care received by older people in the last three months of life and potential differences in care between 2000-2010.

**Methods:** Data were collected with structured questionnaire from proxies of deceased sample-members of the Longitudinal Aging Study Amsterdam (LASA) in 2000 (n=270, response 79%) and 2010 (n=167, response 59%).

**Results:** People in the 2010 sample were significantly older and had a lower functional ability, compared to the 2000 sample. Over the ten-year period, people were less likely to receive no care (15% versus 38%) and more likely to receive formal home care (35% versus 15%). People in the 2010 sample, aged over 80 and males were more likely to receive formal and institutional care, than informal or no care. Regardless of the study year, people with a better functional ability and people receiving informal or formal home care, were more likely to die in hospital.

**Conclusions:** New is that this study found an influence of time affecting received care, independent of age, gender, functional status, marital status and educational level. Two scenarios of care in the last three months of life arise from the data: staying at home as long as possible with a higher chance of dying in hospital or living in a residential or nursing home, reducing the chance of dying in hospital. In the future, timely transfer to residential or nursing home therefore may reduce the percentage of hospital deaths. On the other hand older people might prefer staying at home, accepting the higher chance of dying in hospital.

**Main source of funding:** The Netherlands organisation for scientific research (NWO)

**Abstract number:** P426
**Abstract type:** Poster

**How to make an implementation of the national recommendations for terminal care to work - a possibility to Finnish Researches**

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**Aim:** The aim is to develop a questionnaire to study the attitudes and basic knowledge of students and people working in social and health care towards suffering, death, the hospice and terminal care.

**Background:** Ministry and the Ethical Board (ETENE) has recently launched the recommendations for terminal care in Finland. The recommendations emphasise the human dignity and right of self determination of the dying individual. A researchers’ forum was organized to find different methods and tools to the implementation of the recommendations. The first step was to study attitudes and knowledge of selected groups.

**Methods:** A questionnaire was developed basing to the Finnish recommendations. Data were collected from 292 persons: 86 practitioners, 138 nurse students and 68 medical students.

**Results:** There are differences between the three groups both in the attitudes and the basic knowledge. The differences
are shown in tables 1 and 2. In attitudes the dealing with sorrow and keeping up the hope differs between students and practitioners. The students felt more negative feelings like guilt and depression while thinking work with dying patients, especially the medical students felt guilty about patient’s death. In attitude approaches also the practitioners answers differs more from knowledge base in their own group.

Conclusion: According to the statistical analyses, some items of the questionnaire need to be re-formulated in order to reach better reliability. The questionnaire shows interesting results reporting future different palliative care publications.

Relevance to clinical practice: This study contributes to a new understanding of the attitudes and basic knowledge of terminal and hospice care. The results will help us to focus the educational interventions in the future. The questionnaire tool is planed to be used widely in Finland and also in the forthcoming research about the differences in terminal care culture in Finnish hospices and in Estonia hospice care.

Abstract number: P428
Abstract type: Poster

Funding Models in Palliative Care: Who Pays and how?

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Aim: To assess methods for commissioning and financing palliative care services.

Methods: We undertook literature scoping to identify and appraise models of palliative care financing internationally.

Results: Our literature search identified three predominant funding models.

1) The first is the ‘national’ method, where responsibility for delivery and funding palliative care lies with the national health care system (e.g. Sweden and Australia). Australia is the only country that has developed a patient-based casemix classification (reflecting complexity of needs) to underpin the funding model. Sufficient similarities exist in population demographics and service provision between England and Australia to make this an appropriate method to support progress towards a per-patient funding model in England.

2) The second is the ‘insurance-based’ model, e.g. in the US, where most palliative and end-of-life care services are funded by insurance organisations (either private, or government-linked such as Medicare and Medicaid), or in Germany, where palliative care is funded by health care insurance through per-diem rates, diagnosis related groupings (DRGs), or through the German Remuneration Scheme.

3) The third is the mixed model, where a combination of different financing methods is adopted e.g. in Canada, palliative care funding is partly dependent on location of care; provisional health plans cover care provided at home or hospital, private insurance covers some home care, and private payments supplement care in long term care facilities. For a number of countries, there is no defined or integrated system for the funding of palliative care.

Conclusions: Methods for commission and financing palliative care differ significantly across the world. Only one country, Australia, has created a patient-level casemix classification system to underpin palliative care funding. This work may provide the best available evidence to inform a per-patient level funding model in England.

Abstract number: P429
Abstract type: Poster

Medical, Nursing and Allied Health Professionals’ Views on the Use of Cardiopulmonary Resuscitation in an Irish Hospice

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Background: A policy relating to decisions about cardiorespiratory resuscitation (CPR) was introduced at Milford Hospice in October 2011. CPR policies are well accepted and present in many acute hospitals. In a hospice setting research shows that CPR is indicated in very few patients. (Thorns and Ellershaw 1999) The traditional view of palliative care being synonymous with terminal care has changed and more patients are admitted to hospices for symptom management. (Costello and Horne 2003) Some patients in this group who are actively treated may benefit from CPR.

Objectives: The aim of the study is to investigate the views of doctors, nurses and allied health professionals (AHP) on the use of a CPR policy at this 30-bed specialist palliative care inpatient unit following its introduction.

Methods: A questionnaire enquiring about views on CPR, discussions with patients and factors important in making decisions about resuscitation will be distributed to staff. Ethical approval was obtained from the local research ethics committee.

Results: 35 questionnaires were returned. Although 87% of respondents could foresee a situation in which a patient might be for CPR at the hospice only 54% either agreed or strongly agreed with the presence of a CPR policy in a hospice setting. Only 40% of respondents had either BLS or ACLS training in the last 3 years. Less than half (46%) thus felt confident in initiating CPR at the hospice. 43% felt that CPR should be discussed with patients whom it is felt that it might restart the heart and maintain breathing while 37% felt...
that it should be discussed with all patients admitted to the hospice. The top 4 factors felt to be important when making decisions about resuscitation were the patient’s prognosis, diagnosis/extent of disease, wishes and performance status. 

**Conclusion:** The introduction of a CPR policy in the hospice has raised several ethical and practical issues. CPR decisions are necessary to ensure those who might benefit have the option to discuss them. This survey has given us an understanding of the staff's views and will help with addressing these issues and enable successful implementation of the policy.

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**Abstract number:** P430  
**Abstract type:** Poster  

**What Is the Difference between Japan and EAPC White Paper in Palliative Care?**  

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**Purpose:** It is important to develop for hospice/palliative care that the organisation expresses their opinion or statement by an official report called white paper. Japanese hospice foundation (JHF) and European Association for Palliative Care (EAPC) have had almost same history of palliative care nationally from 1970’s. Therefore we compared with white paper published by JHF and by EAPC in last decade.  

**Subjective and method:** We searched ICHUSHI and Google Scholar in Japanese and MEDLINE and Google Scholar in English at the time of September 30th, 2011. We used by two key words such as white paper and palliative care.  

**Result:** We hit ten palliative care white papers by JHF from 1998 to 2010. Also we got five white papers in palliative care published by EAPC from 2004 to 2010.  

**Discussion:** The character of JHF white paper is to collect data in particular field in the past. It was historical and collective papers. The themes of every Japanese white paper were short history, sensus, associating organizations, team members, palliative care team and PCU, Japanese Cancer Act, Audit, palliative care in the community. On the other hand that of EAPC white paper statement paper was a Retrospective Explorative Study  

**Conclusion:** It is quite a different character between JHF and EAPC white paper in palliative care. The Japanese one is historical-oriented and domestic but the European one is future and worldwide-oriented.
Aims: The main goal of palliative care is to gain more insight into crises and critical care for advanced cancer patients. The occurrence of crises in palliative care decreases the quality of life of advanced cancer patients and their family. The aim of this study is to gain more insight into crises and critical care for advanced cancer patients.

Methods: This explorative research study had a quantitative, retrospective, descriptive design. The data were extracted from 124 medical records of adult advanced cancer patients hospitalised for critical care in 2009 in a University Medical Centre (UMC), hospital (H) and two hospice facilities (HF) in the province of Utrecht, the Netherlands. Data were collected from January to April 2010.

Results: Crises were the main cause of hospitalizations of advanced cancer patients (63.1%). The average length of stay was 11.3 days. Patients were hospitalized for symptom treatment (UMC:60%, H:50%) and social indications (HF:75%). The crisis interventions were physical, focussing on treatment of the main cause(s) of the crisis (UMC: 100%, H:92%) and social, focussing on acceptance of the crisis as a sign of nearing death (HF:75%). The caregivers’ burden, use of homecare services, physicians’ contact rate and decision-making process were not documented.

Conclusion: Critical care for advanced cancer patients is a significant proportion of inpatient palliative care. Hospitalisation is often caused by an accumulated crisis, which indicates time and space for prevention. Prevention does not seem to be fully implemented in homecare and healthcare institutions, leaving room for improvement of symptom management.

In addition to the results found in this explorative study a prospective study will provide more knowledge on crises in palliative care. Early access to palliative home care, prevention of crises and use of the screening instruments to assess symptoms and family caregivers’ burden are goals of a new conducted study.

Abstract number: P434
Abstract type: Poster

Family Caregivers as Members of Palliative Care Team: Something New or Something Old?

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A century ago, care to the dying was largely administered in the home by the family, neighbours, friends - sometimes with the support of a visiting family doctor. Proliferation of hospitals and access to national health insurance resulted in the institutionalization of dying. Technological innovation supported this process and resulted in an ever-increasing knowledge gap between physicians and their patients. Globalization and demographic shifts have also contributed to the burden family members face when caring for their loved ones. As a result, family caregivers have been largely relegated to the sidelines in the institutional care of the dying. These same forces however have provided family members with improved education, income and resources. Education and empowerment have also altered the relationship between the average individual and their physician. Family members as a result are more likely to comprehend and willing to take part in the care process. In both Finland and Canada, parents have become members of the care team in neonatal intensive care units. Preliminary evidence suggests improved clinical and economic outcomes. A question therefore arises whether this model is working or would work in palliative care settings? We therefore propose a model of care which embraces family caregivers as fully-fledged members of an interdisciplinary team on a tertiary palliative care unit. This hypothetical experiment describes the shift in nursing care to incorporate training and the agreement of some family members to work ‘shifts’ and take part in the interdisciplinary care conferences. This model of care takes advantage of family members’ presence on palliative care units. We hypothesize that family comprehension and satisfaction with care will increase and that patients outcomes will improve. The skills and knowledge gained by families should enable earlier discharge from institutional settings and reduce some of the burden they currently face.

Abstract number: P435
Abstract type: Poster

Participation of High Grade Glioma Patients in End-of-Life Treatment Decision-making

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Context: Several decision-making models on patient participation exist. The shared model is often considered ideal, but studies give rise to the question whether this model is most suitable in all situations or all patient groups. Overall aim is to investigate which decision-making models for patient participation can be recognized in end-of-life treatment decisions and how appropriate these models are.
for patients with high grade glioma (HGG).

**Design:** Qualitative study using observations and interviews.

**Methods:** Eligible patients are HGG patients in whom it has to be decided whether or not to start a life-prolonging treatment, but with the disadvantage of burdensome symptoms of treatment. The first interview with patients about preferences in participation takes place previous to a decision at the patients’ home. After that, patient-physician conversations will be observed at the outpatient clinic. After a decision has been made, patient and physician will be interviewed separately to discuss perceived participation in decision-making and their satisfaction.

**Results:** 14 patients are included until August 2011, in 5 patients a life-prolonging treatment decision is made up till now. Age ranges between 27 and 82. Patients differ in their preferred level of participation. Passive patients mentioned trust in physician and lack of knowledge as explanations for their preference, active patients mentioned keeping control of their own life. We observed a difference in preferences in participation between life prolonging treatment decisions and minor decisions such as change of daily medication. Patients with similar involvement in decision-making classified their participation differently.

**Conclusion:** Even in this specific group, patients vary in their preferences for involvement in treatment decisions. Similar situations were experienced and interpreted differently by different patients.

**Main source of funding:** The Netherlands organisation for scientific research

**Abstract number:** P436

**Abstract type:** Poster

**Respecting the Autonomy at the End-of-Life of People with Intellectual Disabilities**

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**Background:** In people with intellectual disabilities (ID), respect for autonomy has to match with the cognitive and communicative possibilities and impairments of these persons. Since most people with ID are highly dependent on others, they need responsible and caring caregivers to maintain their autonomy at the end-of-life.

**Aim:** To gain insight into how relatives and professionals can respect and support autonomy of people with ID in the very last phase of life.

**Methods:** In this qualitative study 12 cases of recently deceased people with ID were reconstructed. Half of them died of cancer, while the others died from other chronic diseases or ‘old age problems’. A total of 47 relatives, doctors, social workers and nurses were interviewed using a semi-structured topic list. A cyclic process of data collection and qualitative analysis was used to reach saturation.

**Results:** Attitudes and skills that are important for respecting the autonomy of people with ID at the end-of-life are:

1. Paying attention to the - often changing - information needs, preferences and capacities, as well as attention to the patient’s response to the information and care given;
2. Taking responsibility for communication with and involvement of the person with ID in decision-making;
3. Being creative in finding ways to involve people with ID in decisions;
4. Careful assessment how the person with ID responds to attempts of involving him or her in decisions and communication processes.

**Conclusions:** Respect for autonomy requires that professionals and relatives are proactive and alert. They must carefully establish what needs are, and explore ways to involve patients with ID in end-of-life decisions. They have to communicate with the patient in such a way that (s)he feels safe to be receptive for information. This also implies that relatives and professionals are alert to signs of whether care decisions are either undermining or constructive for the autonomy of the person with ID.

**Abstract number:** P437

**Abstract type:** Poster

**Medical Oncologists’ Perception of Palliative Care Programs and the Impact of Name Change to Supportive Care on Communication with Patients during the Referral Process. A Qualitative Study**

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**Background:** In a simultaneous care model, patients have concurrent access to both cancer-directed therapies and palliative care. As oncologists play a critical role in determining the need/timing of referral to palliative care programs, their understanding of the service and ability to communicate this with patients is of paramount importance. Our study aimed to examine oncologists’ perceptions of the supportive care program at our institution, and to determine whether renaming “palliative care” to “supportive care” influenced communication regarding referrals.
Methods: This qualitative study used semi-directed interviews, and analyzed data using grounded theory and qualitative methods.

Results: We interviewed 17 oncologists. Supportive care was perceived as an important time-saving application, and symptom control, transitioning to end-of-life care, family counseling, and improving patients’ ability to tolerate cancer therapies were cited as important functions. Although, most claimed that early referrals to the service are preferable, oncologists identified several challenges, related to the timing and communication with patients regarding the referral, as well as with the supportive care team after the referral was made. While oncologists stated that the name change had no impact on their referral patterns, the majority supported it, as they perceived their patients preferred it.

Conclusions: Although, majority of oncologists favorably viewed supportive care, communication barriers were identified, which need further confirmation. Simultaneous care models that effectively incorporate palliative care with cancer treatments need further development.

Abstract number: P438
Abstract type: Poster

What Is the Nurses’ Understanding of Palliative Care?

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Introduction: Very often, specialized palliative care service access for patients who needed it is delayed. The early intervention in the course of illness could improve the quality of care and prevent the crisis events by improving symptom management and quality of life. Our hypothesis is that nurses have misconceptions about palliative care, considering referral only when the disease is at terminal stage.

Methods: First, our team conducted a study exploring physicians’ representation in 2008, and we replicate this study using the same questionnaire but for nurses in the same university hospital.

Results: 172 questionnaires were sent and we received 107 answers (62 %). One of two nurses thinks that that the palliative care referral is not adapted in an early stage. They are afraid of generating patient anxiety. They felt difficult to determine the right time for a palliative care referral. Pain was the first symptom justifying a referral to the palliative care team, but they did not report any other symptom. The other reasons reported for referral to palliative care were support, comfort, and accommodation. The psychosocial distress, or family distress were quoted less often.

Conclusion: Despite 5 years of training and information with nurses, palliative care understanding is still linked with the end of life care.

Abstract number: P439
Abstract type: Poster

InfoPAL: Introducing Shared Palliative Care Electronic Records to Underpin Continuity of Care, Regional Resource Coordination

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Background: Information is important for all organizations; how it is collected, verified processed and used has direct effect on clinical activity. Data must be registered using agreed and understandable methodology. An electronic system allows for data analysis to aid research, audit, management and/or health planning. Giving up paper medical records must not make a complicated care. It must mean an improvement in its continuity, favour data reading and analysis. The reality of electronic medical records shared by all assistential levels constitutes an interesting outcome indicator which incorporates technology to the Coordinating systems.

Aim: To facilitate and promote the design, implementation and adoption of new Information and Communication Technologies (ICT) for a large population.

Methods: Using the regional strategy, its objectives, requirements and over all needs to approach the project were established. It was developed from an Information Systems viewpoint and with continuity of care and Palliative Care (PC) specificity premises. PMI-PMBOOK has been used for the project management and CMMI methodology for Software development. PC Master Registry has been incorporated to AP-Madrid Registry (Primary Care Clinical Notes).

Results: A PC Information System has been created (infoPAL) accessible from all care levels 24 hours a day and a Regional PC Registry with up-to-date clinical and administrative information.57 professionals have piloted the system from all clinical settings in a given regional PC sector for 773793 citizens.

Conclusions: PC complex interventions and continuous clinical situation change benefit from accessible up-to-date information. We have established that new ICT use is an asset in this multidisciplinary, with multiple resources to proportionate the necessary means to identify patients and register PC information. It also unifies the jeans to be able to know quality, costs and population PC level evolution in an amazing cost-effective fashion.
Holistic Palliative Care: An Illusion? Why Patients Don’t Speak about their Spirituality with their Physicians and Nurses

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**Background:** Although palliative care generally aims at integration of physical, psychosocial and spiritual dimensions of care, patients sometimes deliberately hold back their spiritual concerns from their professionals. If knowledge were available of why patients conceal their spirituality, professionals could decide if and how they would like to discuss spirituality.

**Aim:** To explore why palliative care patients withhold their spirituality from their physician or nurse.

**Method:** Prospective interview study. We theoretically sampled on variation in age, sex, disease and housing. The semi-structured interviews were transcribed. Making use of a hermeneutic phenomenological approach, we analyzed the role of spirituality. Two researchers independently coded some interviews and the results of the analyses were discussed until we reached consensus.

**Results:** 11 cancer patients, 8 severe COPD patients and 4 severe heart failure patients (N=23) were included (12 men, 11 women). Mean age: 66 yrs (37-91 yrs). Interviews lasted about 10-90 minutes. Especially palliative care patients who had a spirituality that was not linked to a church or institute did not discuss their spirituality with their physician or nurse. The reason for this was that they felt ashamed of the non-rational character of their spirituality or because they assumed their physician/nurse had no knowledge of spiritual concerns. They stated, in addition, that their physician/nurse should (only) help them with their bodily concerns.

**Conclusion:** Palliative care patients had several reasons to hide their spirituality for their physicians/nurses, which confirmed the results of other studies that in some parts of the world it is difficult to integrate the spiritual dimension into palliative care. It is important for palliative care professionals to recognize their patients’ (hiding of) spirituality in order to improve their communication.

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Collecting Living Wills and Preferences Regarding End of Life: Feasibility in Patients with Non Curable Cancer

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**Background:** The patients’ rights and end of life (EOL) law passed in 2005 in France has reinforced patients’ autonomy. However patients and professionals are ill-informed and the opportunity for patients to designate a surrogate or to express advanced directives is scarcely used. Whereas information programs have been evaluated in most countries, research on this topic is still needed in France.

**Aims:** To assess the feasibility of collecting wills and preferences regarding EOL care in patients with metastatic lung cancer. Secondary objective is to identify patients’ and oncologists’ barriers to address such topics.

**Methods:** An information procedure was designed and assessed for feasibility in incurable patients recruited consecutively after psychological evaluation. This procedure has been further developed to collect patients’ living wills. It consists in 2 semi-structured interviews: the first one aims to inform patients and to evaluate their questioning about EOL options, the second one (taking account of first interview and patients’ context and defense mechanism) aims to elaborate on, individual wills can be orally explored or collected in written. Interviews are recorded and held by a trained oncology fellow and a palliative care nurse.

Feasibility assessment relies on interviews’ acceptance rate and proportion of patients whose wills are actually collected. Barriers to this approach are drawn from qualitative content analysis. Anxiety is measured at the end of interviews. Oncologists’ beliefs and attitudes regarding EOL discussions are evaluated using a structured questionnaire.

**Results:** Ongoing test of the information procedure has enabled to create an interview framework tailored to patient’s questioning and attitude regarding EOL options. Feasibility and ability to actually collect living wills are to be formally evaluated on 20 patients.

**Conclusion:** Results will enable to put into practice a systematic evaluation of living wills in oncology setting.

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Crises in Palliative Care: A Concept Definition

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**Abstract number:** P442

**Abstract type:** Poster
Introduction: Palliative care focuses on the quality of life of patients and families. The occurrence of crises reduces quality of life.

Aims: To define the concept crisis in palliative care.

Methods: A Grounded Theory study was performed from September-December 2009. Participants were selected by purposive sampling. Data were collected through in-depth interviews starting with the question: “What are crises in palliative care?” All interviews were transcribed verbatim, contributing to the researchers’ theoretical sensitivity. Constant comparison was applied. Data were coded in 3 levels. Data and analyses were peer reviewed and peer debriefed by 2 researchers. Trustworthiness and rigour were ameliorated by interview training, triangulation, member check, memos and decision trail.

Results: The participants were 7 palliative care specialists (doctors and nurses), from different care settings. Crisis in palliative care was defined as: “the experience of a disruption of the patient system causing an acute healthcare consultation.” Crises can be caused and influenced by all members of the patient system. Experience, the main concept, was assessed as anxiety, despair and panic caused by the feeling of lack of control. Crises were either acute (e.g. bleeding), or accumulated (e.g. uncontrolled symptoms). Crises decreased the quality of life of advanced cancer patients, and caused hospitalizations.

Conclusion: Healthcare professionals define crises in palliative care as an experience. However, in emergency care settings they tend to refer to crises as acute care situations. This neglect of the patients (and family) experience could cause feelings of loneliness or being misunderstood and thereby a risk for under treatment.

The prevention of accumulated crises should focus on the methodological and systematical assessment of (future) symptoms and (future) care problems within the patients’ system. Prevention of crises is a challenge in palliative care.

Abstract number: P443
Abstract type: Poster

Novel Method for Determination of Δ9-tetrahydrocannabinol (THC) in Cancer Patient Serum by High-performance Liquid Chromatography with Electrochemical Detection

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Aim: Δ9- tetrahydrocannabinol (THC, dronabinol), one of the psychoactive constituents of cannabis, has been used for anti-emetic treatment as well as orexigenic effects in chemotherapy for cancer patients. THC has not been marketed in Japan; but it is important to establish a simple and accurate measurement method for THC concentrations in blood since control of the blood concentration of THC within safe ranges is indispensable for patients receiving THC. In Japan, no simple and rapid assay for THC is yet available. Furthermore, it is necessary to ascertain the pharmacokinetics of THC in blood. Herein, we endeavored to develop a method for measuring THC concentrations in the blood of cancer patients.

Methods: Chromatograms were obtained using a PU-2080 pump (Nihon Bunko) equipped with an electrochemical detector, Coulochem III (Nippon Dionex). The column was the XTerra® RP18 (5μm, 4.6mm×50mm i.d., Waters Japan) set at 25 °C. The mobile phase was 50mM KH2PO4/CH3CN (3:7). The voltage of the working electrode of the electrochemical detector was set at 800mV. Serum samples (1.0 mL) were extracted in 4 mL butyl chloride. The samples were then mixed, centrifuged for 10 minutes, and the butyl chloride (top layer) was transferred to a clean glass tube. The butyl chloride extract was then evaporated to dryness. The dried residue was dissolved in 100μl ethanol, and 5.0μl of the solution were injected into the HPLC column.

Results: The THC peak was detected in 4.2 minutes and separated well from the serum component. The recovery rate was 91.6%. A linear-regression analysis of the standard curve from 10 ng/mL to 100 ng/mL yielded the following equation; y=520.31x-712.68 (r =0.999). The lower limit of quantification was 1.0 ng/mL.

Conclusion: The present THC measurement method is simple and rapid, and detection sensitivity equivalent to that of the conventional method was obtained. Therefore, it should be useful for measuring THC concentrations in blood from cancer patients.

Abstract number: P446
Abstract type: Poster

How Effective Are Trial Methodologies in Palliative and End of Life Care Research? A Review of the Literature

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Background and aims: The difficulties in carrying out research into palliative and end of life care have been well documented, and include (amongst other issues) poor recruitment to trials, high rates of attrition and complicated consent processes at the end of life. This review aims to investigate the methodological effectiveness of different trial designs that have been used in palliative and end of life research.

Methods: The review has followed a systematic approach to the identification and screening of the literature.
The databases AMED, British Nursing Index, Embase, Medline, Psychinfo were searched using a combination of palliative and methodological key words. Papers were included if they reported findings from a trial of a palliative or end of life intervention (involving patients not carers) and provided discussion on matters of trial design, recruitment, attrition or other areas of methodological performance.

Results: 55 papers out of an initial 443 remain after full paper screening. The data set includes a mix of feasibility and full trials, using a variety of trial designs (RCT, cluster, crossover, fast track) to assess a number of different intervention types (IMP, service, psychosocial, complementary). In our approach to reporting we aim to identify and distinguish between 'successful' and 'unsuccessful' trials, provide an overview of the key methodological features of these trials (including quality appraisal based on CONSORT statements) and explore thematically success factors, along with areas of difficulty, challenges and recommendations for future trials, as identified by individual paper authors.

Conclusions: To be identified-work in progress.

Abstract number: P447
Abstract type: Poster

Factors Influencing Participation in a Cancer Mortality Followback Survey

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Aims: To determine the predictors of bereaved relative participation in a mortality followback survey.

Methods: A mortality followback survey, 1516 bereaved relatives of cancer patients from four health regions in London (UK) were identified from death registrations covering one year period (2009/10). Sample stratified by death at home (n=368), hospital (513), hospice (512), nursing home (123). Respondents (n=596) and non-respondents (920) were compared on socio-demographic variables using parametric (t-test) and non-parametric tests (Mann-Whitney, Chi² and Fisher’s exact tests), univariate and multivariate logistic regression.

Results: Four factors - patient age (P< 0.001), place of death (P=0.021), informant gender (P< 0.001) and relationship to patient (P< 0.001) were found to be independently associated with participation. The odds of taking part in the study were highest if the patient was aged 90+ (OR 3.46, 95% CI 1.51 to 7.94) and the informant of death was female (OR 1.70, 95% CI 1.33 to 2.16). The odds of participating were lowest if the patient died in hospital (OR 0.62, 95% CI 0.46 to 0.84) and the informant of death was not a spouse/parent (ORs ranged 0.63 for siblings to 0.28 for others). Social deprivation was only marginally significant (P=0.053) and non-linear. Time following death (median 7 months), patient gender, country of birth, cancer type and health region were not independently associated with participation (P>0.05).

Conclusion: Consistent with other studies, women and relatives of older patients were more likely to respond. In contrast to other studies, time following death and social deprivation did not influence participation. Relatives of people who died in hospital were less likely to respond. Further analysis of reasons for refusal may help identify ways to capture the views of less represented groups, either by increasing research participation in surveys or designing alternative studies.

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Abstract number: P448
Abstract type: Poster

Improving Palliative Care in Dementia and Cancer: Organisation of Palliative Care - Study Protocol

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Aims: To gain detailed insights into the models of palliative care (PC) for dementia and cancer across Europe through the development and application of an analytic framework that captures differences between health care systems and disease-specific differences. This is part of the IMplementation of quality indicators in PAlliative Care’sTudy (IMPACT); a European Commission funded project. There is wide consensus that PC in particular for dementia is in need of improvement and better organisation. However, little has been published on the actual problems and issues within PC.

Methods: A mixed methodology approach will be used starting with extensive literature reviews to gather information on healthcare systems and identify publications or organisation interventions in PC. Realist synthesis methods will help map service provision across Europe of nursing homes, hospitals, home care, hospice and networks. We will survey existing literature, to identify the range and organisation of services available. Additionally a web based survey of INTERDEM and EAPC members to identify the range and quality of services available. This will enable us to triangulate data to build up a comprehensive map of
services and service deficiencies. Interviews with policy makers involved in the organisation of PC will confirm commonalities and further explore variance of the European countries and PC for dementia and cancer. The findings of these methods will be discussed at consensus conferences to reach consensus about the critical aspects of palliative care and the key elements of high quality service provision.

**Results and conclusion:** The outcome will be a description of services, healthcare delivery patterns, nation specific characteristics, a description of “best practices” in palliative care for these two patient groups, and an analytic framework to characterise PC across Europe.

**Abstract number:** P449  
**Abstract type:** Poster

**A Presentation of the Nation-wide Strategic Policy Research Project Flanders Study to Improve End-of-Life Care and Evaluation Tools (FLIECE Study)**

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**Aims:** To promote better palliative and end-of-life care (EOLC) in Flanders the FLIECE project was conceived, with a threefold aim

1) to assess the quality of palliative care and EOLC and how it can be improved  
2) to test and improve existing and novel evaluation tools and interventions for EOLC, and  
3) to evaluate societal changes in EOLC and end-of-life decision-making.

**Methods:** A consortium of leading EOLC research groups from 4 universities was composed to work out FLIECE and solicit for funding from the agency for Innovation by Science and Technology. This presentation describes

1) which aspects were included in the working program,  
2) how the strategic policy research requirements were met in order to get funding.

**Results:** The project is constructed around the 3 main strategic aims and contains 8 separate studies aimed at

1) avoiding unnecessary hospitalization at the end of life,  
2) timely recognition of palliative care needs by GPs,  
3) improving EOLC communication,  
4) improving EOLC in residential care for older people,  
5) evaluation of the quality of EOLC in care homes and in acute geriatric wards,  
6) in acute geriatric wards,  
7) developing quality indicators in palliative care, and  
8) societal evaluation of EOLC and decision-making in Flanders.

Risky and novel research methodologies are applied to address the research aims.

All studies are aimed at both obtaining scientific evidence and developing and delivering concrete intervention tools based on the evidence (eg handbooks, training programmes) aimed at improving EOLC in collaboration with relevant sectors and actors.

An elaborate dissemination strategy was outlined to make sure results will reach relevant societal actors. The project received a 2.6 million € funding (2011-2014).

**Conclusions:** By focusing on interventions to improve the quality of palliative and EOLC and on the testing of evaluation tools, the strategic aims of the FLIECE project focus directly on a combination of scientific research and societal dissemination of the results.

**Abstract number:** P450  
**Abstract type:** Poster

**Refinement of the Global Map of Palliative Care Development**

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**Background:** In 2006 the first ‘world map’ of palliative care development was produced. It contained a four-part typology applied to the 234 countries of the world:

1) no identified hospice-palliative care activity  
2) capacity building activity  
3) localized palliative care provision  
4) palliative care approaching integration with mainstream service providers.

**Aim:** To refine the original ranking system of palliative care development and make the categorisation more robust.

**Method:** In 2011, groups 3 and 4 were sub-divided to produce two additional levels of categorization. Data about levels of palliative care development were collected from a number of sources. In a process of self-evaluation, ‘key persons’ were asked to rank the level of palliative care development in their country against the typology. Each country was allocated to one of six categories:

1) no known hospice-palliative care activity  
2) capacity building activity  
3a) isolated palliative care provision  
3b) generalized palliative care provision  
4a) countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision
4b) countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision.

**Results:** In 2011, 136 of the world’s 234 countries (58%) have one or more hospice-palliative care service established - an increase of 21 countries (+9%) since 2006; the most significant gains have been made in Africa. Although there are indications of palliative care interest on the part of national governments and policymakers, advanced integration of palliative care with wider health services has been achieved in only 20 countries globally (8.5%).

**Conclusion:** Using the revised typology, levels of palliative care development were categorized and depicted in a series of world and regional maps in order to facilitate cross-national comparative analysis and stimulate advocacy, policy making and service development.

**Abstract number:** P451  
**Abstract type:** Poster  
**Title:** Refinement of the EAPC Task Force on the Development of Palliative Care in Europe Facts Questionnaire  
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**Background:** Many difficulties have been identified in comparative studies of palliative care development. A challenge facing the European Association for Palliative Care (EAPC) Task Force on the Development of Palliative Care in Europe has been the standardisation of terms such as ‘hospice’, and ‘inpatient unit’, which do not have a universal currency and have therefore made comparison of services difficult.

**Aim:** To refine the EAPC Facts Questionnaire (a quantitative study that collects ‘factual’ data on palliative care service provision).

**Method:** The Facts Questionnaire was refined by the Task Force during 2011; each individual question was reviewed for relevance and clarity. The method for selecting ‘key persons’ was revised with the President of each National Palliative Care Association requested to nominate a ‘key person’ with extensive local knowledge of palliative care to complete the questionnaire, along with another list of potential contacts that could be used to peer-review the completed EAPC Country Report. If a country had no National Palliative Care Association, ‘key persons’ were selected through previous participation in the original Task Force project, personal recommendation from existing ‘key persons’, or because they have become known to members of the Task Force whilst participating in other similar projects.

**Results:** The EAPC Facts Questionnaire has been refined to improve the quality of data collection. The content and structure of the 2011 version differs significantly from the original version; for example, a new section on specialized palliative care services has been developed based on the EAPC White Paper on Terminology of Palliative Care Services which provides a clearer definition of relevant terms.

**Conclusion:** Building on lessons learned, the Task Force has undertaken a substantial refinement of the EAPC Facts Questionnaire in order to improve the quality of data collection and associated comparative international palliative care studies.

**Abstract number:** P452  
**Abstract type:** Poster  
**Title:** Access to Opioid Medication in Europe (ATOME) Country Profile Methodology  
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**Background:** The International Observatory on End of Life Care (IOELC), as part of its remit within the Access to Opioid Medication in Europe (ATOME) project, is responsible for compiling country profiles for twelve European target countries: Estonia, Latvia, Lithuania, Poland, Slovakia, Hungary, Slovenia, Serbia, Bulgaria, Greece, Turkey, Cyprus.

**Aim:** Describe the rationale and procedures used to identify barriers and opportunities in gaining access to controlled medicines within each country.

**Method:** The country profiles incorporate mixed method designs to gather data on access to controlled medicines. A common template on key structural issues is used for each country, thereby allowing effective comparison between countries and regions. Qualitative data is collected from interviews with key activists at ATOME National Workshops. Quantitative data is obtained from relevant public health, demographic and ethnographic websites. Data relating to opioid consumption is gathered from the Pain and Policy Study Group’s database Drug Control and Access to Medicines Consortium (DCAM).
Results: The country profiles enable variations and similarities in access to controlled medicines across the 12 target countries to be critically examined. Comparative analysis of these contexts makes it possible to witness the degree of progression or regression in access to controlled medicines in each respective country and also functions as a benchmark to enable countries to ascertain the degree to which their situation compares with others in their region.

Conclusion: The ATOME country profiles combine qualitative information on political, social, and health care policy and related factors with quantitative data in order to illuminate the socio-cultural context within which access to controlled medicines is positioned. The country profiles act as a resource for policy and service development pertaining to controlled medicine usage in the twelve identified European countries.

Abstract number: P453
Abstract type: Poster

Measuring what Matters: The Case for Qualitative Research in Palliative Care Clinical Trials

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Aims: Key ethical issues such as informed consent and obtaining the patient perspective are central to the conduct of clinical trials and their contribution to clinical medicine. There has been ongoing debate about how best to investigate these issues, especially in more vulnerable patient populations. Qualitative research has an established tradition within the fields of health, illness and social care research due to its focus on the meaning rather than the measurement of experience.

Methods: This discussion extends understanding of the contribution of qualitative research to Investigational Medicinal Products (IMP) clinical trials through describing the research design and findings of the QualZICE study, which explored the experiences of patients with advanced breast cancer participating in the ZICE clinical trial (oral vs IV bisphosphonate treatment).

Results: Clinical IMP trials with embedded qualitative designs are still in their infancy but are essential for exploring issues in relation to trial processes and participant experience. A range of qualitative techniques may be used to investigate how participants make sense of particular sets of experiences within wider social, cultural and personal contexts, and may be used to explore difficulties with recruitment or participant understanding of trial processes. Methods of in depth data collection such as semi structured interviews, focus groups or observation are best suited to collect such data, but as an alternative or complementary method, open questions could also be included on questionnaires.

Conclusion: It remains to be said that such methodologies need to be applied appropriately and by suitably experienced researchers, which means factoring in sufficient time and funds to help maximize the potential value and contribution of this growing field of research.

Abstract number: P454
Abstract type: Poster

MORECare Research Methods Guidance: Methodological Challenges in Developing and Evaluating Palliative and End of Life Care (EoLC) Services

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Aims: There is increasing demand for palliative and EoLC services, yet the evidence base to inform these developments is inconsistent hampered by methodological challenges. We aimed to systematically review the research methods used in studies evaluating these services to inform best research practice.

Methods: We searched six databases. Inclusion criteria were systematic reviews on the effectiveness of generalist and/or specialist palliative care (SPC) services for patients with advanced illness and/or their families. Narrative synthesis informed the review with the MRC framework developing and evaluating complex interventions guiding the data analysis.

Results: 26 systematic reviews were included, 15 specialist, 9 generalist and 2 mixed palliative care services for patients with cancer (7), advanced chronic disease (10) or mixed populations (9). The findings showed prominent methodological challenges as: intervention modelling; recruitment precision; confronting randomisation; and economic evaluation beyond cost savings. Modelling the intervention to identify confounders was essential, but rarely undertaken and requires greater collaboration with stakeholders. Research studies were hampered by inadequate small size, compromised by passive recruitment and limited incorporation of common issues. Randomised
controlled trials (RCT) were commoner in evaluations of generalist services, while SPC incorporated RCT and non-randomised designs requiring greater incorporation of successful designs. Economic evaluation was limited to cost savings, with reviewers advocating incorporation of informal and formal care costs alongside effectiveness data.

**Conclusion:** Best research practice requires emphasis on intervention modelling to improve recruitment and study design. Greater emphasis is needed on multicentre trials of services that encompass all phases of the MRC guidance, and cost-effectiveness data. This has implications for research training, collaboration and funding.

**Abstract number:** P455  
**Abstract type:** Poster  
**Feasibility of a New Out-patient Breathlessness Support Service**

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**Background:** Breathlessness is a common and devastating symptom affecting many patients with advanced malignant and non-malignant disease. Management comprises non-pharmacological and pharmacological interventions best delivered by a multidisciplinary group. Aim is to describe the feasibility of a study testing a newly established Breathlessness Support Service (BSS) at King’s College Hospital, London.

**Methods:** An innovative BSS with palliative care and respiratory medicine (consultant, nurse, physiotherapy occupational therapy, and social work) input is offered since October 2010 to patients with refractory breathlessness due to advanced malignant and non-malignant disease. Patients are seen twice in the clinic and offered a home visit by physiotherapy or occupational therapy. The new service is evaluated in a phase 2 fast track randomised controlled trial (RCT) comparing immediate or delayed (after 6 weeks) access to BSS.

**Results:** Since October 2010, 119 patients have been referred to the study, of which 18 did not meet the inclusion criteria, 15 declined participation, 5 have died, 19 were uncontactable and 7 were waiting for inclusion. Referrals come from across settings with physiotherapy and respiratory medicine as main referrers. 53 patients (27/53 male; mean age 65 y (range 46-84 y); 35/53 carer present; 31 COPD, Cancer 12, 6 ILD, heart failure 4) have consented to take part in the RCT of which 35 have completed the study primary end-point (6 weeks). Attrition rate is 13%, 2 patients withdrew, 3 patients died and 2 were lost due to administration problems. The BSS is well received by patients. Main organisational problems relate to transport to the BSS and patients being unwell to attend the second clinic visit.

**Conclusion:** Referral to the study is similar to what we expected but uptake is much less than we anticipated (approximately 45%). Once in the trial, attrition is low. Overall, the BSS seems to be feasible.

**Abstract number:** P456  
**Abstract type:** Poster  
**MORECare Developing Methods Guidance: Recommendations for Outcome Measurements in Palliative and End-of-Life Care (P&EoLC) Trials and Intervention Studies**

**Evans C.J.1, Benalia H.1, Preston N.2, Short V.3, Todd C.1, Grande G.3, Gysels M.1, Bausewein C.1, Daveson B.A.1, Higginson I.J.1**

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**Aim:** Outcome measurement in P & EoLC research is challenging, especially in clinical trials and evaluations of interventions. There is need for methods guidance on outcome measurement properties, timing and use of proxies. Our aim was to identify agreed best practice in selecting and using measures and create methodological guidance for research.

**Methods:** We used the MORECare Transparent Expert Consultation approach at an outcome measurement summit at the 2011 EAPC conference to generate recommendations and then a web based survey. Participants were invited with backgrounds in palliative care and research. Participants developed potential recommendations in groups and then ranked and commented on them. The recommendations were then combined and presented in the survey. We then invited summit delegates and the MORECare Project Advisory Group to provide further ranking and comments.
**Results:** 31 experts attended the summit. 29 recommendations across the 3 areas were presented in the survey. The top recommendations by areas were:

1) measurement properties should be responsive to change over time and capture clinically important data, and be easy to use and administer;
2) data collection time points require clear identification to establish a baseline, and end points need to correspond to when the intervention effect is expected;
3) enhancing the validity of proxy data requires clear and specific guidelines to aid individuals’ completion of proxy measures, and data from patients and proxy measures should be differentiated in the database. Areas of divergence included measures crossing practice, audit and research, and use of proxies.

**Conclusion:** It is recommended that in P&EoLC intervention studies outcome measures are easy to use, responsive over time, are administered at baseline and appropriate follow up points, and have clear instructions. Use of proxies are important sources of data but requires validation. Areas of divergence require further research.

**Abstract number:** P457

**Abstract type:** Poster

**Methods Guidance on Developing and Evaluating Palliative and End of Life (P&EoLC) Services; The MORECare Research Project**

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**Aims:** Development in P&EoLC services are needed but are hampered by a weak evidence base. The MORECare project aimed to identify, appraise and synthesise best practice methods to develop and evaluate P&EoLC services and produce guidance.

**Methods:** Our methods included: systematic literature reviews, expert-consensus meetings and on-line consensus. We assess the relevance of all phases of the Medical Research Council Guidance on Developing and Evaluating Complex Interventions (MRC GDECI) and selected topics lacking evidence and/or of main concern for further analysis and consensus.

**Results:** Systematic reviews appraised:
1) the extent that studies followed MRC GDECI,
2) nature of trials conducted,
3) research participation and
4) recruitment.

Six topicspecific expert consensus meetings were undertaken, followed by on-line ranking to agree priorities and identify divergence. Priorities were agreed, but discordance was found in health economics and some other in topics. User workshops and consultation with policy stakeholders identified the need for the guidance to be user friendly and the challenge to work with political timelines. Very little work has been undertaken on implementation, but examples of good practice were identified in palliative care. The final guidance includes evidence based recommendations in: study design selection; service modelling and development; recruitment; involvement of patients in studies; ethical considerations; mixed methods; measurement of end points and outcomes; economic evaluation; statistical analysis to manage missing data and attrition; and implementation. Algorithms and case studies demonstrate ways of applying the recommendations in research practice.

**Conclusion:** The MORECARE Guidance addresses methodological challenges of P&EoLC research. There are recommendations for study design and education, notably training research ethics committee members, funding body members and academics/practitioners in palliative care.

**Abstract number:** P458

**Abstract type:** Poster

**Research Priorities in Spiritual Care: Results of a Pan-European Survey by the EAPC Spiritual Care Taskforce**

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**Background:** The EAPC Spiritual Care Taskforce was launched in April 2011 with the aim of determining how to meet the spiritual needs of patients and their families in all palliative care (PC) settings. While spiritual care is a core component of PC, it is neglected in clinical practice and research. An informed research strategy is essential to guide the development of evidence-based spiritual care.
Aim: To determine PC clinicians’ and researchers’ priorities for research in spiritual care, to inform the development and implementation of a European research agenda in this area.

Methods: The Research Subgroup of the Taskforce developed an online survey sent to all delegates (n=6000) of the EAPC Lisbon congress for completion in November 2011. The survey asked respondents whether there is need for more research to inform the provision of spiritual care in the context of PC; those answering in the affirmative were asked to select the 5 most important research priorities from a designated list of 14 topics (e.g. prevalence of spiritual distress in different cultural/religious populations, effectiveness and cost-effectiveness of spiritual care, spiritual care in dementia). Respondents were asked to state additional research priorities and their relative importance, the single research question they believed to be most important, and the methodology most appropriate to answer it. Demographic data (e.g. belief system, professional occupation) were collected. Descriptive statistics were used to explore the data and rank research priorities by importance.

Results: Complete findings from the survey will be presented. Identified research priorities of EAPC delegates will be used to construct a research agenda to inform collaborative European research in spiritual care.

Conclusion: This pan-European survey is the first of its kind in spiritual care. The EAPC Spiritual Care Taskforce will be building on the resulting research agenda in coming years. [No funders]

Abstract number: P459
Abstract type: Poster

Experiences of a Clinical Trial: QualFRAG

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Aims: Palliative care lung cancer patients are underrepresented in oncology trials and very little is understood about their experiences of participating in clinical trials. FRAGMATIC is the largest lung cancer study in the UK and is investigating the effects of Fragmin (a self-injected anti-coagulant) in patients with lung cancer. This current study (QUALFRAG) is a qualitative sub-study of the FRAGMATIC trial which aims to explore:

1. Prioritisation and management of symptom burden over time;
2. The psychological impact of participation in a clinical trial for advanced lung cancer patients (intervention and control), with particular emphasis on equipoise;
3. The acceptability of long-term heparin as a therapy in advanced lung cancer;
4. The impact of clinical trial monitoring processes in terms of a positive attention affect and the implications for service modelling.

Methods: Semi-structured interviews be held at three time points, with two groups of six to ten patients (12 to 20 in total) recruited from the intervention and control arms of FRAGMATIC. Interviews will be analysed using Interpretative Phenomenological Analysis to identify emergent themes that reflect participants’ lived experience.

Preliminary results: To date, four patients (two per trial arm) have completed their first interview. Recruitment and analysis will be complete by time of conference. Key areas discussed include: motivations for participation; understanding trial information and randomisation; impact of a non-placebo trial on hope and coping; research nurse support; symptom management and progression; acceptability of long term heparin.

Conclusion: Preliminary results indicate that patients do not always understand the process of randomisation, raising the question as to whether they truly give informed consent to participate. Ethical issues are also raised when considering the impact of a non-placebo trial on feelings of hope and the coping processes of palliative lung cancer patients.

Abstract number: P460
Abstract type: Poster

Ten Good (?) Reasons Not to Screen for Depression in Palliative Care

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Few Palliative Care Services or individual palliative care clinicians have adopted recommendations supporting systematic screening for depression. This is despite official recognition by the World Health Organisation that psychological assessment and care is a core component of the definition of palliative care. This is despite high level recommendations to screen for depression coming from professional bodies and government affiliated organisations. This is also despite widespread recognition of the burden of depression among palliative patients, its persistence, the extent to which it can adversely affect patients’ behaviour
and medical condition, and its association with patient satisfaction with treatment, and despite a wide variety of validated screening instruments for depression being available.

In order to understand this disconnection between clinical practice and official recommendation, it is necessary to examine arguments and evidence for and against such screening. Although other papers have addressed barriers to screening for depression, this paper is innovative in acknowledging that reservations about screening for depression often reflect reasonable concerns.

This review uses the UK National Screening Committee criteria as a framework for organising relevant research in palliative care, and where this is not available, evidence that exists in other aged and medically ill populations. Previous reviews have focused almost exclusively on the effectiveness of such screening in initiating treatment and reducing levels of depression in affected patients. They have not addressed other costs and benefits of screening for depression that are likely to influence clinicians’ decisions.

Abstract number: P461
Abstract type: Poster

What’s Another Year? Level 2 Palliative Care Provision within a Continuing Care Setting - Staff Views & Perspectives
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Background: Provision of level 2 palliative care is a recent innovation in Ireland. At Our Lady’s Hospice & Care Services level 2 care has been integrated into existing continuing care structures. Care is delivered by a multidisciplinary team (MDT) augmented by sessional support from the Palliative Care Advanced Nurse Practitioner and a registrar. Little research has been undertaken to elicit views of staff about these preferences, and the influence of having an advance directive (AD) on this.

Aims: Advance care planning concerns the anticipation on the needed and preferred care in due course. People may already have ideas about their end-of-life preferences before being ill, or develop them later. We aimed to study the preferences of older people in the last three months of life on forgoing treatments, the change in and discussion about these preferences, and the influence of having an advance directive (AD) on this.

Methods: We performed a retrospective cross-sectional quantitative study of a sample deceased members of two cohort studies: the Longitudinal Aging Study Amsterdam (LASA), representative for the Dutch older population and the Advance Directive Cohort (ADC) consisting of people with an AD. Participants were proxies (LASA n=168; ADC n=184) of deceased sample-members of age 57 and over. Data were collected via a structured written questionnaire.

Results: 125 questionnaires were distributed with a response rate of 51% (n=54). 38% of respondents were nurses (n=24) with smaller representation of other members of MDT. Symptom assessment, management and psychosocial care score demonstrated a high level of confidence. From the qualitative data themes included increased staff workload, time constraints around addressing psychosocial issues and suboptimal interdisciplinary communication. Conversely, some staff felt stimulated and enriched by their experiences.

Conclusion: Level 2 provision continues to evolve with demand exceeding supply. Non specialist palliative care staff have largely embraced the challenges inherent in caring for this new patient cohort whose needs can be complex. New innovative approaches to support and meet learning needs of staff are being developed.

Abstract number: P462
Abstract type: Poster

Having and Discussing Preferences on Forgoing Treatment in the Last Three Months of Life of Older People with and without an Advance Directive
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Aims: Advance care planning concerns the anticipation on the needed and preferred care in due course. People may already have ideas about their end-of-life preferences before being ill, or develop them later. We aimed to study the preferences of older people in the last three months of life on forgoing treatments, the change in and discussion about these preferences, and the influence of having an advance directive (AD) on this.

Methods: We performed a retrospective cross-sectional quantitative study of a sample deceased members of two cohort studies: the Longitudinal Aging Study Amsterdam (LASA), representative for the Dutch older population and the Advance Directive Cohort (ADC) consisting of people with an AD. Participants were proxies (LASA n=168; ADC n=184) of deceased sample-members of age 57 and over. Data were collected via a structured written questionnaire.

Results: While only 16% of the population have an AD, about half of the older population in the Netherlands had preferences on wanting to receive or to forgo treatment decisions on resuscitation, artificial administration of fluids and nutrition, antibiotics and artificial respiration. For over 8 out of 10 older people preferences did not change between 3 months and 3 days before their death. Having an AD was the most important factor associated with preferring (non-
Geriatric Palliative Care Models Based on the Perceptions of - And Attitudes toward End-of-Life Needs and Demands of Target Population

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24 experts from the fields of Health and Social care, Justice, Economics, Sociology, Gerontology and Geriatrics have identified that: I. Demography, illnesses’ structure, family income, health insurance, legislative and social securities formulate the necessary predictors for creation of Geriatric Palliative Care Model (GPCM) (abstract, EAPC XI Congress, Lisbon, 2011); II. To create such model, the perceptions (P) of- and attitudes (A) toward end-of-life (EL) needs (N) and demands (D) of aged population itself obviously should be taken into account. Supposedly these P&A are significantly determined by recognition of the limited lifespan. The similar situation is seen in patients with cancer, who really recognize their limited life terms.

**Aim:** To offer palliative care research teams from different countries to participate in multi-center surveys for “Mapping and Comparative Analysis of P&A toward ELND groups of People with Recognized Limited Lifespan due to Different Causes”.

Three groups will be studied: I -“Healthy” elders (80 years and more), continuing social activity, though recognizing the limited terms of remaining life;

II - Terminal patients with cancer recognizing their prognosis and the limited terms of remaining life;

III - Control group - healthy people of middle age.

The research will be based on respondents’ semi-structural interviews designed with two main questions:

"Tell us about your life” and “What do you think about future?” Supportive questions will be selected according to: Maslow’s pyramid of needs, results of studies by Chochinov et al., TOE model, model of behavioral analysis on logical levels by G. Bateson. The interviews will be audio-taped, transcribed and coded for further cluster analysis by computer program QSR NVivo9.

Study results will support: the correct understanding of the ELND; creation of reasonable background for the development of optimal GPCM; perfection of the palliative care model for cancer patients.
Conclusions: A social science approach can offer a perspective on cultural beliefs and practices that would not be captured using a single disciplinary approach.

Abstract number: P465
Abstract type: Poster

Management of Neuropathic Pain (NP) Using the Capsaicin 8% Patch in Patients with Cancer

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Background: Many patients with cancer experience NP but pharmacological treatments often deliver only partial analgesia and are associated with adverse effects. A single application of the capsaicin 8% patch can provide relief from NP for 12 wks. We describe our experience using the capsaicin patch to treat patients with cancer-associated NP.

Methods: All patients treated with the capsaicin patch between June 2010 and August 2011 were included in the analysis. Pain levels were assessed using an 11-point scale as part of the PainDETECT questionnaire and the Clinical Global Impressions Scale.

Results: A total of 23 patients (21-71 yrs) were treated with the capsaicin patch. Pain diagnoses included chemotherapy-induced peripheral neuropathies (n=14), post-surgical complex cancer pain with areas of focal NP (n=8) and post-herpetic neuralgia (PHN) (n=1). Seventeen patients received one application, four received two, and two received four applications. Pain score reductions 4-8 wks after treatment were >90% in 12 patients (Table). The capsaicin patch was particularly effective in patients with chemotherapy-induced neuropathy (CIN). In most patients analgesia was reported after 24 hours and was sustained. Importantly, analgesia was linked to increased activities that were previously limited by pain. Significant reductions in use of opioids and systemic NP medications were seen. Data for >50 patients treated between June 2010 and May 2012 will be presented.

Conclusions: These preliminary data, the first in patients with cancer treated with the capsaicin patch, show significant and sustained benefit across a variety of patients. Further evaluation in this setting is warranted.

<table>
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<th>Type of pain</th>
<th>&lt;50%</th>
<th>50-90%</th>
<th>&gt;90%</th>
<th>Awaited</th>
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<td>1 (13)</td>
<td>2 (25)</td>
<td>4 (50)</td>
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<tr>
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<td>1 (7)</td>
<td>10 (71)</td>
<td>1 (7)</td>
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<tr>
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<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total (n=23)</td>
<td>3 (13)</td>
<td>3 (13)</td>
<td>12 (52)</td>
<td>5 (22)</td>
</tr>
</tbody>
</table>

[Table]
Abstract type: Poster

Communication with People with Dementia: Person-centered and Gender-sensitive Aspects in Palliative Care

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Aims: Finding good ways of living together with people with dementia becomes increasingly important. Professionals in health care, social care and elderly care are confronted with a growing need for person-centered and gender-sensitive communication in palliative care. The aim of the project presented is to give recommendations for those involved in every day palliative care engaged in general health and social care institutions.

Methods: A multilayered data collection and analyses has been conducted: 1. A systematic review that assesses the evidence of skills training for persons with dementia. 2. An in depth literature research on person-centered and gender-sensitive communication. 3. A research project that yielded two case studies concerning methods of person centered communication in nursing homes. 4. Two interdisciplinary qualitative group discussions in hospitals with the question: What are the major challenges in communication with persons with dementia?

Results: The recommendations for health and social care professionals for person-centered and gender-sensitive communication were published as a brochure by the ministry of health. They include “methods of communication”, “person-centered communication”, “gender-sensitive communication”, “end-of-life care”, “narratives from hospital and long term care settings”, “evidence based skill trainings”, “organisational development and evaluation” and “helpful resources”.

Conclusions: The results show that person-centered and gender-sensitive communication with people with dementia is a major challenge in health and social care institutions. Communication has to be valued as core competence for palliative care with people with dementia. Emotions play a vital role in contacts and care relationships. Changing communication behaviour within institutions always need supportive organisational culture and structures that give time and room for meaningful interactions.

Abstract number: P469

The Use of Complementary and Alternative Medicine by Irish Paediatric Cancer Patients

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Introduction: The use of complementary and alternative medicine (CAM) is on the rise. To date however the use of CAM in the Irish paediatric cancer setting has not been established.
Methods: In order to investigate the prevalence and predictors of CAM use in this group an anonymous cross-sectional survey was offered to all carers of patients attending for treatment of malignancy or follow up outpatient clinic at a single paediatric cancer centre over an 8-week period.

Results: Of a total of 220 questionnaires that were distributed, 98 (43%) were returned. Of these 6 were excluded because of inadequate data. Of the 92 questionnaires available for analysis 58% of children were male and the mean age was 9 years. The most common cancer diagnosis was leukaemia (45%).

Tumours. Median duration of treatment was 12,5 months (range: 24-83). 40 had hematologic cancers, 37 solid tumours. Median duration of treatment was 12,5 months (range: 1-129). Data on the last 14 days of life were available for 50 patients. 42 of these patients received aggressive EoL treatment within the last 14 days of life. Only 11 patients died supported by or in a palliative care institution. Discussion of EoL issues was documented in 36 of all 77 patients, but intensity of treatment was not influenced by prior EoL discussion (p = .248, χ² test).

Conclusion: The high prevalence of CAM use demonstrated in this study and particularly the high use of CAM medication therapies underlines the importance of physicians asking routinely about CAM use in this population.

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Icelandic Nurses’ Experience of Using the Liverpool Care Pathway for the Dying Patient in Palliative Care Units

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Nurses working in palliative care units are responsible for the delivery of palliative and end-of-life care to their patients in the dying phase. The main purpose of Liverpool Care Pathway for the Dying Patient (LCP) is to assure the delivery of high quality care to dying patients. It is a multiprofessional process based on evidence based knowledge. The purpose of the study was to explore the experience of palliative care nurses in using the LCP in X. The methodology chosen for the study was the Vancouver School of doing phenomenology. Thirteen nurses from two palliative care units were interviewed. Findings revealed that the nurses perceived the Pathway as milestones when caring for the dying patient. The nurses also felt that the main aspects of care in the dying phase were interconnected in the Pathway, they found it helpful in leading the way to optimal care and valued it when the focus of care had to change. Furthermore, they experienced more confidence and ambition in delivering care, more effective communication with relatives and increased professional awareness. None of the nurses would wish to be without the Pathway when
caring for dying patients in the palliative care unit, though some expressed concerns regarding aspects which they felt needed to be changed, improved or taken notice of. The results indicate that the LCP has a valuable role in the palliative care unit settings according to the nurses sampled. The study gives insight into the nurses’ experience of using the LCP in palliative care units and is of value understanding and developing this sensitive area of practice.

Abstract number: P473
Abstract type: Poster

Identifying Chronic Advanced Patients in Need of Palliative Measures in the General Population and Health Services: A Prevalence Study

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Aims: To establish prevalence, place of care and mortality of chronic advanced patients in need of palliative care in the County of Osona (population of 153,500 inhab). It has a comprehensive system for geriatric, dementia, palliative and chronic care and a common information system linking all the Health Care Services.

Methods: Cross-sectional and observational prospective cohort study. 3 of 11 primary care areas (30.5% of population distributed in rural, rural-urban and urban sectors) have been selected to participate, as well as general hospital of the county (1) and socio-health center (1) and nursing homes (4) located in studied area. Both physician and nurse, individually and in each setting, will review their lists of patients with chronic illnesses to elaborate, jointly, a list of patients having advanced chronic conditions (first method). NECPAL tool will be applied to them. When having the surprise question negative and, at least, 1 more parameter positive, they will be considered as a NECPAL + (second method). Patients will be followed for survival until 12 months. Overall mortality of patients in studied area will also be followed.

Statistical analysis: Prevalence will be established. Sensibility, specificity, PPV, NPV and AUC ROC for both methods will be assessed regarding mortality at 3, 6, 9 and 12 months. Kaplan-Meyer method and LogRank test will be applied to compare survival curves between identified and non-identified patients with both methods.

Results: 9 of 9 care centers accepted to participate. Patient recruitment has just finished in October 2011. Preliminary results at 6 months will be available in June 2012.

Conclusion: Knowledge of the prevalence of patients with advanced chronic diseases and limited life prognosis is a fundamental basis for planning and implementing palliative care programs with a public health, community and population-based approach.


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Abstract type: Poster

Patients’ involvement in decision making about their care: a qualitative longitudinal study in Greece

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Aim: To explore the ways cancer patients are involved in their care and decision making about their care in the six months prior to their death.

Methods: A longitudinal qualitative approach was adopted, employing an ethnographic methodological framework. Fourteen advanced cancer patients were intensively followed over 6 months each, as they came into contact with an oncology setting and other health care services in Athens. Patients, 34 family members, and 32 health professionals involved in their care were interviewed (total 75 hours) and observed (total 830 hours). Data was managed with N-Vivo and analysed using thematic analysis and case study analysis.

Results: Three models of involvement were identified: 1) direct communication with the health professionals (actively seeking for information/participation in decision making); 2) involvement through families (requesting their family to advocate) and 3) relying on the doctors (trusting doctors as knowing best). There were aspects of decision-making that all patients chose to be actively involved with: a) care plans near the end of life b) maintaining their role within the family and c) assuring the space and time for their dying preparation. Five factors were found to influence the model of involvement adopted over time: 1) patient’s age, 2) the specific decision to be made, 3) the prior role the patient had in the family 4) the transition point in the illness trajectory and 5) the meaning they granted to their life and death.

Conclusion: This study identifies three models of patient involvement, however the level of involvement changes as
disease progresses and is influenced by social, contextual and cultural issues. Understanding the factors influencing patient involvement is vital to the planning care and services sensitive to patients’ needs.

Abstract number: P475
Abstract type: Poster

Feasibility of Assessing Quality of Care at the End of Life from Two Multicentre Cluster Trials

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Aims: In 2009 and 2010 two multicentre cluster trials were undertaken with the aim of improving quality of care at the end of life through the implementation of the LCP for the Dying Patient in hospital wards and hospice. According to the MRC Framework, they can be classified as a randomized phase III and a before/after phase II cluster trial respectively. This study was aimed at exploring the feasibility of the assessment at baseline.

Methods: We analyzed compliance to the protocol procedures using multiple assessment, and compared the results from hospices and hospital. Data was gathered through:
1) the family caregiver’s assessment of the last week of life
2) GPs feedback on communication with hospital wards or hospices
3) interviewers’ evaluation of comprehension and impact of interviews on caregivers
4) recording of clinical procedures in the last 3 days of life.

Results: 69.1% of hospital and 55% of hospice patients were male. Lower standard of education was found amongst patients in hospital (30.9% having high level education in hospital, 45.1% in hospice). This was also reflected amongst caregivers, with 9.9% of hospital caregivers having only basic schooling, compared with 5.3% of hospice. The length of stay of the last admission was 1-62 in hospital, and 1-361 in hospice.

1) 117 out of 152 hospital (77%), and 99 out of 131 hospice patient’s caregivers (75.6%) were interviewed, with 84 (71.8%) hospital and 78 (78.7%) hospice interviews undertaken face to face
2) The percentage of hospital and hospice GP interviewed was similar in both samples (84% and 85.5% respectively)
3) Information from interviewers was obtained in 97.8% of hospital and in 97% of hospice cases
4) Preliminary results suggest over 95% compliance.

Conclusion: Compliance is high with all assessment procedures, and similar between the two settings. These findings support the feasibility of the strategies developed for effectively assessing information about quality of care in both the trials.

Abstract number: P476
Abstract type: Poster

Pharmacokinetics and Tolerability of Fentanyl Buccal Soluble Film (FBSF) in Cancer Patients with Oral Mucositis

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Research aims: Fentanyl buccal soluble film (FBSF) (Breakyl, Meda AB, Sweden) is a small film that rapidly delivers fentanyl through the buccal mucosa into the systemic circulation. Then, it dissolves spontaneously. FBSF is indicated for the treatment of breakthrough cancer pain. The purpose of this study was to compare the pharmacokinetics of fentanyl from FBSF in patients with cancer, with and without grade 1 oral mucositis, and to assess its tolerability in this population.

Study design and methods: In an open-label, single-dose study, two groups of patients with cancer received a 200 µg dose of FBSF. Patients in cohort I (n = 7) had grade 1 mucositis, and patients in cohort II (n = 7) were age- and gender-matched controls without mucositis. The FBSF dose was placed on the area of mucositis in cohort I and on a matching location in cohort II. Blood samples were collected up to 4 hours after administration, and safety assessments were made throughout the study.

Method of statistical analysis: Descriptive statistics were calculated to summarize the pharmacokinetic parameters.

Results: Patients in the oral mucositis cohort had a mean AUC0-4 of 88% of the value observed for those patients without oral mucositis, and the mean Cmax in the oral mucositis cohort was 68% of the mean Cmax observed in the group without oral mucositis.

This finding is of practical importance because if the absorption of fentanyl in patients with an altered mucosa was substantially greater, unexpectedly rapid rises in fentanyl plasma levels may lead to opioid-related adverse events. A possible clinical implication for this finding is that patients with cancer who are also experiencing mucositis may require slightly higher doses of FBSF than patients without mucositis. Local tolerability was good, as no local reactions occurred, even though the FBSF was directly applied on the mucositis area. There were no deaths or serious adverse events.

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