Corticosteroid prescribing in palliative care settings: A retrospective analysis in New Zealand

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BACKGROUND: Corticosteroids are a potent group of medicines, with many adverse effects, that are widely prescribed in palliative care for both specific and non-specific indications. The aim of this study was to document current patterns of corticosteroid prescribing in New Zealand palliative care settings and to reflect on whether they were in line with international experience. METHODS: A retrospective review of inpatient use of corticosteroids was undertaken in a sample of six New Zealand hospices. Data were collected on numbers of patients prescribed corticosteroids, indications for use, choice of agent, doses and dosage changes, duration of course, incidence of adverse effects, method of stopping, use of guidelines, and processes for monitoring and review. RESULTS: The case notes of 1179 inpatients were...
reviewed and 768 patients (65.1%) had received at least
one course of corticosteroids. There was a marked con-
sistency in the proportion of patients prescribed corti-
costeroids among the sample hospices (61–69%).
Detailed information was recorded for a sample of
260 patients. Corticosteroids were prescribed most
commonly for non-specific reasons (40.4% of prescrib-
ing events), followed by neurological (25.3%) and soft
tissue infiltration symptoms (14.4%). The agent of
choice was dexamethasone with a dose range of
1–40 mg and a median dose of 8 mg. The median
course duration for all corticosteroid prescribing
events was 29 days. Abrupt stopping occurred in 72
(23.2%) cases, of these 35 (49%) had been on a
course of corticosteroids for more than 3 weeks.
Guidelines were only available in one hospice.
Monitoring and review were documented in 135
(52%) of cases, and adverse effects were recorded in
82 (32%); these are likely to be underestimates due to
a high level of non-recording. CONCLUSIONS: This New Zealand study showed that corticosteroids
are widely prescribed in palliative care, most com-
monly for non-specific indications. These findings
are consistent with the international literature in this
area and this large, multi-site study adds weight to
the findings and the need for ongoing discussion
about the place of these drugs in palliative care.

**PPC/2014/General 2**

**Evolution of cancer-related symptoms over an
18-month period**

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CONTEXT: Previous studies have revealed inconsistent
findings about the longitudinal evolution of cancer-
related symptoms. In addition, the contribution of
medical factors (e.g. cancer site and treatments) in
explaining the changes in these symptoms is yet to be
established. OBJECTIVES: This prospective study
investigated longitudinal changes of five symptoms (i.e.
depression, anxiety, insomnia, fatigue, and pain) in
patients scheduled to undergo surgery for cancer (*N =
828*).

METHODS: The patients completed the
Hospital Anxiety and Depression Scale, the Insomnia
Severity Index, the Multidimensional Fatigue
Inventory, and a pain questionnaire at baseline and
after 2, 6, 10, 14, and 18 months. RESULTS: Several
time changes were statistically significant but effect
sizes only revealed one change of a medium magnitude,
that is, a reduction of anxiety from T1 to T2 (*d = −0.58*).
Women with breast or gynecological cancer were the
only subgroups to exhibit significant changes (i.e.
duction of a small magnitude of anxiety symptoms
from T1 to T2; *ds = −0.27 and −0.30*, respectively).
However, numerous differences were found across
adjuvant treatments, including greater variations in
depression and insomnia scores in the chemotherapy
group (*ds = −0.71 to 0.20*) and a transient increase in
fatigue symptoms in patients receiving ‘all’ adjuvant
treatments (*ds = −0.24 to 0.37*). CONCLUSION: The
severity of cancer-related symptoms varies during the
cancer care trajectory, especially anxiety scores, which
importantly decrease during the first few months after
the surgery. This study also suggests that treatment regi-
mens better account for individual differences than
cancer site in the evolution of symptoms.

**PPC/2014/General 3**

**Enrollment and events of hospice patients with
heart failure vs. cancer**

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*J Pain Symptom Manage.* 2013;45(3):552–60

CONTEXT: Hospice care is traditionally used for
patients with advanced cancer, but it is increasingly con-
sidered for patients with end-stage heart failure.

OBJECTIVES: We compared enrollment patterns and
clinical events of hospice patients with end-stage heart
failure with those of patients with advanced cancer.

METHODS: Using Medicare data linked with phar-
macy and cancer registry data, we identified patients
who were diagnosed with either heart failure or advanced
cancer between 1997 and 2004, admitted to hospice at
least once after their diagnosis, and died during the
study period. We compared patterns of referral, use of
acute services, and site of death of hospice patients
with heart failure with those of patients with advanced
cancer. Logistic regression models were constructed to
determine the factors associated with late hospice enroll-
ment as well as the use of and death in acute care.

RESULTS: We identified 1580 heart failure patients and
3840 advanced cancer patients: mean ages were 86
and 80 years, 82 and 68% were women, and 97 and
94% were White, respectively. Compared with patients
with advanced cancer, those with heart failure were
more frequently referred to hospice from hospitals (35
vs. 24%) and nursing facilities (9 vs. 7%) (both
*P < 0.01*). Discharge from hospice before death was similar
for patients with heart failure and patients with advanced
cancer (10 vs. 9%, *P = 0.03*). Among patients remaining
in hospice, patients with heart failure were more likely to
have been enrolled within 3 days of death (20 vs.11%,
*P < 0.01*). The prevalence of death in acute care settings
was low in both groups after hospice enrollment (4% heart
failure vs. 2% advanced cancer, *P < 0.01*). Although the median interval between enrollment and
death was shorter for heart failure patients (12 vs. 20
days, *P < 0.001*), emergency department visits and
hospitalizations after hospice enrollment were more
frequent in patients with heart failure (13 vs. 10% and
9 vs. 6%, respectively, both \( P < 0.01 \). CONCLUSION: Compared with patients with advanced cancer, referral to hospice is more often initiated during acute care encounters for patients with end-stage heart failure, who also more frequently return to acute care settings even after hospice enrollment.

**PAEDIATRIC ISSUES**

*PPC/2014/Ped 1*

**Parents’ perspectives on the deaths of their children in two Brazilian paediatric intensive care units**

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*Int J Palliat Nurs.* 2013;19(10):495–502

OBJECTIVES: To evaluate the quality of care offered to terminally ill children and their families in the last days of life in two Brazilian paediatric intensive care units (PICUs) from the parents’ perspectives. METHODS: This was a qualitative, exploratory study. Parents of a child who had died in one of the PICUs 6–12 months previously were invited to take part in two interviews: a private meeting with the PICU assistant physician who cared for their child, to discuss and review any outstanding issues related to the diagnosis, treatment, and prognosis, and a recorded interview with a researcher who was not involved in the child’s treatment. Data from the interviews with the researcher were posteriorly grouped in categories according to recurrent terms. RESULTS: Six categories emerged, three of which are reported here. The quality of communication was low; the medical staff frequently used technical terms, limiting understanding. Parental participation in the decision-making process was scarce; decisions were based on the medical perspective. Finally, families reported uncompassionate attitudes from the medical staff and excessive technology in the final moments surrounding the child’s death, although nurses were highly involved with palliative care measures and demonstrated sympathetic and supportive postures. CONCLUSION: The interviews uncovered deficiencies in the care provided to parents in the PICUs, indicating a need for changes in practice.

*PPC/2014/Ped 2*

**Bereaved caregivers as educators in pediatric palliative care: Their experiences and impact**

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*J Palliat Med.* 2013;16(6):699–15

BACKGROUND: With the continuing growth of pediatric palliative care, there is an increasing need to develop effective training for healthcare professionals. Bereaved parents have participated in the training of healthcare professionals utilizing curriculum from the initiative for pediatric palliative care (IPPC), but the experience of bereaved parents as educators has not been studied. OBJECTIVES: This qualitative research examined the experience of bereaved parents involved in pediatric palliative care education of healthcare professionals and the challenges and possible benefits for the healthcare professionals. METHODS: Nine bereaved parents and 11 healthcare professionals were interviewed about their experiences in a pediatric palliative care education program utilizing the IPPC curriculum. The interviews were recorded, transcribed, coded, and analyzed for themes and subthemes. RESULTS: Major themes found were a sense of purpose for the parents and benefits and challenges for both parents and professionals. The experience for parents contributed to their meaning-making for both their children’s lives and deaths. Parents and professionals identified mutual learning and increased mutual understanding. Some professionals noted that the presence of parents may have limited the openness of discussion of the professionals and parents acknowledged challenges of emotional management in their participation in the educational program. Both parents and professionals recognized and described challenges involved in working sensitively with patients and families without being overwhelmed by the intensity of situations where children die. CONCLUSION: More benefits than burdens were experienced by both parents and healthcare professionals from the participation of bereaved parents in the palliative care trainings.

*PPC/2014/Ped 3*

**Regoaling: A conceptual model of how parents of children with serious illness change medical care goals**

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*BMC Palliat Care.* 2014;13(1):9

BACKGROUND: Parents of seriously ill children participate in making difficult medical decisions for their child. In some cases, parents face situations where their initial goals, such as curing the condition, may have become exceedingly unlikely. While some parents continue to pursue these goals, others relinquish their initial goals and generate new goals such as maintaining the child’s quality of life. We call this process of transitioning from one set of goals to another regoaling. DISCUSSION: Regoaling involves factors that either promote or inhibit the regoaling process, including disengagement from goals, reengagement in new goals, positive and negative effect, and hopeful thinking. We examine these factors in
the context of parental decision making for a seriously ill child, presenting a dynamic conceptual model of regoaling. This model highlights four research questions that will be empirically tested in an ongoing longitudinal study of medical decision making among parents of children with serious illness. In addition, we consider potential clinical implications of regoaling for the practice of pediatric palliative care. SUMMARY: The psychosocial model of regoaling by parents of children with a serious illness predicts that parents who experience both positive and negative effect and hopeful patterns of thought will be more likely to relinquish one set of goals and pursue a new set of goals. A greater understanding of how parents undergo this transition may enable clinicians to better support them through this difficult process.

**PPC/2014/Ped 4**

**Factors associated with the provision of hospice care for children**

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*J Pain Symptom Manage. 2013;45(4):701–11*

**CONTEXT:** Children at the end of life often lack access to hospice care at home or in a dedicated facility. The factors that may influence whether or not hospices provide pediatric care are relatively unknown.

**OBJECTIVES:** The purpose of this study was to understand the institutional and resource factors associated with provision of pediatric hospice care.

**METHODS:** This study used a retrospective, longitudinal design. The main data source was the 2002–2008 California State Hospice Utilization Data Files. The sample size was 311 hospices or 1368 hospice observations over 7 years. Drawing on institutional and resource dependence theory, this study used generalized estimating equations to examine the institutional and resource factors associated with provision of pediatric hospice care. Interaction terms were included to assess the moderating effect of resource factors on the relationship between institutional factors and provision of care. RESULTS: Membership in professional groups increased the probability (19%) of offering hospice services for children. Small- (22%) and medium-sized (11%) hospices were less likely to provide care for children. The probability of providing pediatric hospice care diminished (23%) when competition increased in the prior year. In addition, small size attenuated the accreditation–provision relationship and medium size magnified the membership–provision relationship. CONCLUSION: Professional membership may promote conformity to industry standards of pediatric care and remove the unknowns of providing hospice care for children. Hospices, especially medium-sized hospices, interested in developing or expanding care for children may benefit by identifying a pediatric champion to join a professional group.

**PPC/2014/Ped 5**

**Family factors affect clinician attitudes in pediatric end-of-life decision making: A randomized vignette study**

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*J Pain Symptom Manage. 2013;45(5):832–40*

**CONTEXT:** Conflicts between families and clinicians in pediatric end-of-life (EOL) care cause distress for providers, dissatisfaction for patients’ families, and potential suffering for terminally ill children. **OBJECTIVES:** We hypothesized that family factors might influence clinician decision making in these circumstances. **METHODS:** We presented vignettes concerning difficult EOL decision making, randomized for religious objection to therapy withdrawal and perceived level of family involvement, to clinicians working in three Children’s Hospital intensive care units. In addition, attitudes about EOL care were assessed. **RESULTS:** Three hundred and sixty-four respondents completed the questionnaire, for an overall response rate of 54%. Respondents receiving the ‘involved family’ vignette were more likely to agree to continue medical care indefinitely (P < 0.0005). Respondents who thought that a fear of being sued affected decisions were less likely to pursue unilateral withdrawal (odds ratio 0.6, 95% confidence interval = 0.6–0.9). Those who felt personal distress as a result of difficult EOL decision making, thought they often provided ‘futile’ care, or those who felt EOL care was effectively addressed at the institution were less likely to want to defer to the parents’ wishes (range of odds ratios 0.7–1). **CONCLUSION:** In this randomized vignette study, we have shown that family factors, particularly how involved a family seems to be in a child’s life, affect what clinicians think is ethically appropriate in challenging EOL cases. Knowledge of how a family’s degree of involvement may affect clinicians should be helpful to the clinical ethics consultants and offer some degree of insight to the clinicians themselves.

**PPC/2014/Ped 6**

**Psychometric properties of instruments used to measure fatigue in children and adolescents with cancer: A systematic review**

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*J Pain Symptom Manage. 2013;45(1):83–91*
CONTEXT: Despite the recognized distressing symptom of fatigue in children with cancer, little information is available to assist in the selection of an instrument to be used to measure fatigue. OBJECTIVES: The objectives of this study were to (1) describe the instruments that have been used to measure cancer-related fatigue in children and adolescents and (2) summarize the psychometric properties of the most commonly used instruments used to measure fatigue in children and adolescents with cancer. METHODS: Five major electronic databases were systematically searched for studies using a fatigue measurement scale in a population of children or adolescents with cancer. Fatigue scales used in those studies were included in the review. RESULTS: From a total of 1753 articles, 25 were included. We identified two main fatigue measurement instruments used in a pediatric oncology population: (1) the Fatigue Scale-Child/Fatigue Scale-Adolescent and the proxy report versions for parents and staff and (2) the PedsQL multidimensional fatigue scale. These two scales show similar attributes with reasonably good internal consistency and responsiveness. CONCLUSION: Either the Fatigue Scale or PedsQL multidimensional fatigue scale can be incorporated into clinical research. Future research should focus on identifying specific fatigue measures more suited to different purposes such as comparative trials or identification of high-risk groups.

PAIN AND PAIN RELIEF

Using a morphine equivalence metric to quantify opioid consumption: Examining the capacity to provide effective treatment of debilitating pain at the global, regional, and country levels

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J Pain Symptom Manage. 2013;45(4):681–700

CONTEXT: Morphine has been considered the gold standard for treating moderate-to-severe pain, although many new opioid products and formulations have been marketed in the last two decades and should be considered when examining opioid consumption. Understanding opioid consumption is improved by using an equianalgesic measure that controls for the strengths of all examined opioids. OBJECTIVES: The research objective was to use a morphine equivalence (ME) metric to determine the extent that morphine consumption relates to the total consumption of all other study opioids. METHODS: An ME metric was created for morphine and the aggregate consumption of each study opioid (total ME), adjusted for country population to allow for uniform equianalgesic comparisons. Graphical and statistical evaluations of morphine use and total ME consumption trends (between 1980 and 2009) were made for the global and geographic levels and selected developed and developing countries. RESULTS: Global morphine consumption rose dramatically in the early 1980s but has been significantly outpaced by total ME since 1996. As expected, the extent of morphine and total ME consumption varied notably among regions, with the America, Europe, and Oceania regions accounting for the highest morphine use and total ME in 2009. Developing and least developed countries, compared with developed countries, demonstrated lower overall total ME consumption. CONCLUSION: Generally, worldwide morphine use has not increased at the rate of total ME, especially in recent years. Examining a country’s ability to effectively manage moderate-to-severe pain should extend beyond morphine to account for all available potent opioids.

Plasma morphine and metabolite concentrations are associated with clinical effects of morphine in cancer patients

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J Pain Symptom Manage. 2013;45(4):670–80

CONTEXT: Morphine is the opioid of choice for cancer-related pain, but for many patients the benefits of morphine are outweighed by its side effect profile. Morphine is metabolized to morphine-3-glucuronide and morphine-6-glucuronide; however, little is known about the contribution of these metabolites to analgesia and morphine-related side effects. OBJECTIVES: We investigated the association between plasma morphine and metabolite concentrations and the clinical effects of morphine in cancer patients. METHODS: A prospective study was performed in cancer patients taking oral morphine for moderate-to-severe cancer pain. Subjects who responded well to morphine (responders) and subjects who failed to respond to morphine because of lack of analgesia and/or the presence of intolerable side effects (non-responders/sw itchers) were recruited. Pain and toxicity scores were recorded and blood samples were analyzed for plasma morphine, morphine-3-glucuronide, and morphine-6-glucuronide concentrations. RESULTS: The results showed that (1) morphine responders have higher plasma morphine and metabolite concentrations compared with non-responders, (2) lower pain scores are associated with higher plasma morphine and metabolite concentrations, (3) central side effects are associated with a higher metabolite: plasma morphine ratio, and (4) myoclonus is associated with extremely high concentrations of plasma morphine and metabolites. CONCLUSION: This study has shown that plasma morphine and metabolite concentrations are associated with the clinical effects of morphine therapy. These results are important.
because they demonstrate the relevance of measuring plasma metabolite concentrations in clinical trials and the potential for metabolite data to deepen our understanding of factors that influence an individual’s response to morphine.

**PPC/2014/Pain 3**

**Music therapy reduces pain in palliative care patients: A randomized controlled trial**

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*J Pain Symptom Manage.* 2013;45(5):822–31

**CONTEXT:** Treatment of pain in palliative care patients is challenging. Adjunctive methods of pain management are desirable. Music therapy offers a non-pharmacological and safe alternative. **OBJECTIVES:** To determine the efficacy of a single music therapy session to reduce pain in palliative care patients. **METHODS:** Two hundred inpatients at University Hospitals Case Medical Center were enrolled in the study from 2009 to 2011. Patients were randomly assigned to one of the two groups: standard care alone (medical and nursing care that included scheduled analgesics) or standard care with music therapy. A clinical nurse specialist administered pre- and post-tests to assess the level of pain using a numeric rating scale as the primary outcome, and the Face, Legs, Activity, Cry, Consolability Scale and the Functional Pain Scale as secondary outcomes. The intervention incorporated music therapist-guided autogenic relaxation and live music. **RESULTS:** A significantly greater decrease in numeric rating scale pain scores was seen in the music therapy group (difference in means (95% confidence interval (CI) −1.4 (−2.0, −0.8); P < 0.0001). Mean changes in the Face, Legs, Activity, Cry, Consolability scores did not differ between the study groups (mean difference −0.3 (95% CI) (−0.8, 0.1); P > 0.05). Mean change in Functional Pain Scale scores was significantly greater in the music therapy group (difference in means −0.5 (95% CI) (−0.8, 0.3); P < 0.0001). **CONCLUSION:** A single music therapy intervention incorporating therapist-guided autogenic relaxation and live music was effective in lowering pain in palliative care patients.

**PPC/2014/Pain 4**

**Pharmacological management of non-cancer pain among nursing home residents**

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*J Pain Symptom Manage.* 2013;45(1):33–42

**CONTEXT:** Pain is common in nursing home (NH) settings. **OBJECTIVES:** To describe scheduled analgesic use among NH residents experiencing non-cancer pain and evaluate factors associated with scheduled analgesic use. **METHODS:** We identified 2508 residents living in one of 185 NHs predominantly from one for-profit chain, with pain recorded on two consecutive Minimum Data Set assessments. Pharmacy transaction files provided detailed medication information. Logistic regression models adjusted for clustering of residents in NHs identified factors related to scheduled prescription analgesics. **RESULTS:** Twenty-three percent had no scheduled analgesics prescribed. Those with scheduled analgesics were more likely to have exacerbating pain (5.5 vs. 1.2%) and moderate pain documented (64.7 vs. 47.5%) than residents without scheduled analgesics. Hydrocodone (41.7%), short-acting oxycodone (16.6%), and long-acting fentanyl (9.4%) were common, and 13.8% reported any non-steroidal anti-inflammatory agent use. Factors associated with decreased odds of scheduled analgesics included severe cognitive impairment (adjusted odds ratio (AOR) 0.56; 95% confidence interval (CI) 0.36–0.88), age more than 85 years (AOR 0.57; 95% CI 0.41–0.80), and Parkinson’s disease (AOR 0.55; 95% CI 0.30–0.99). Factors associated with increased odds of scheduled analgesic use included history of fracture (AOR 1.79; 95% CI 1.16–2.76), diabetes (AOR 1.30; 95% CI 1.02–1.66), and higher Minimum Data Set mood scores (AOR 1.11; 95% CI 1.04–1.19). **CONCLUSION:** Some improvements in pharmacological management of pain in NHs have been realized. Yet, the presence of pain without scheduled analgesics prescribed was still common. Evidence-based procedures to assure adherence to clinical practice guidelines for pain management in this setting are warranted.

**PPC/2014/Pain 5**

**Opioid switching in patients with advanced cancer followed at home: A retrospective analysis**

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*J Pain Symptom Manage.* 2013;45(2):298–304

**CONTEXT:** Opioid switching has been found to improve opioid responsiveness in different conditions. However, data on opioid switching performed at home are almost non-existent, despite the fact that most patients are followed at home. **OBJECTIVES:** The aim of this retrospective survey was to determine frequency, indications, usefulness, and safety of opioid switching when treating advanced cancer-related pain in patients followed at home. **METHODS:** A retrospective review of data from patients with advanced cancer followed at home by three home care teams for a period of 2 years was performed. Patients who had their opioids switched were selected. Reasons for switching opioid doses and routes of administration and outcomes were collected.
RESULTS: Two hundred one (17%) of 1141 patients receiving ‘strong’ opioids were switched. The mean Karnofsky Performance Status score was 35.6, and the median survival was 30 days. The most frequent reason to switch was for convenience, and the most frequent switch was to parenteral morphine. In most patients, a better analgesic response was observed. Patients who were switched to parenteral morphine had a shorter survival in comparison with other opioid sequences ($P < 0.0005$). After switching, opioid doses were increased by 23 and 41%, after a week and at time of death, respectively. CONCLUSION: Opioid switching was useful for most patients in the home environment, at least in less complex circumstances, when done by experienced home care teams. Prospective studies are needed to provide information about the decision to admit to hospital for this purpose and the predictive factors that may relatively contraindicate transportation to a facility in severely ill patients.

PPC/2014/Pain 6

**Opioid prescribing practices before and after initiation of palliative care in outpatients**

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*J Pain Symptom Manage.* 2013;45(6):1107–11

CONTEXT: Prescription Monitoring Programs (PMPs) are being developed and implemented in many states to deter abuse, diversion, and overdose, and physicians may use PMPs to help guide their treatment choices for individual patients. OBJECTIVES: To evaluate the changes in prescribing practices and pain score outcomes in patients with cancer before and after an initial consult in an outpatient palliative care clinic. METHODS: This is a retrospective study with a sample of 60 consecutive patients, who had been referred by oncologists for difficult-to-manage pain and whose initial palliative care consult was with either of the two physicians in the outpatient palliative care clinic. For each patient, lists were compiled of all prescriptions for controlled medications and filled for the 90-day periods immediately before and after the initial consult. Data from patient charts were combined with information from the Virginia PMP, which included prescriptions written before and after the initiation of palliative care, written by prescribers both inside and outside the palliative care clinic. RESULTS: After the palliative care consult, the proportion of patients on long-acting opioids increased from 45 to 73%. Self-reported pain outcomes, which were compiled for the subset of patients who continued palliative care for at least 60 days, showed a median decrease of two units on a 0–10 scale. A decrease was seen in the use of medications that compound acetaminophen with opioids. CONCLUSION: Data from a PMP proved useful in understanding the changes in a population of patients. Favorable changes were observed in prescribing practices and pain outcomes.

PPC/2014/Pain 7

**An examination of adherence to pain medication plans in older cancer patients in hospice care**

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*J Pain Symptom Manage.* 2013;45(1):43–55

CONTEXT: Timely and appropriate management of pain is essential to promote comfort at the end of life. OBJECTIVES: To determine if pain-related factors and non-pharmacological interventions affect medication adherence in older cancer patients in community-based hospices. METHODS: The study involved cancer patients aged 55 years and older, newly admitted to one of the 13 community-based hospices in the midwestern USA descriptive design with patients or their proxies providing information during two telephonic interviews and review of their hospice medical records were used. RESULTS: A total sample of 65 patients was obtained, with data directly from 32 patients during Interview 1 (T(1)), 25 during Interview 2 (T(2)), and proxy reports for 33 (T(1)) and 30 (T(2)) patients. The overall mean pain medication adherence scores (maximum 9) for all patients were 8.43 (T(1)) and 8.38 (T(2)). For component analysis (three components; maximum of 3 points each), patients were the least adherent with opioid orders at both timepoints (2.65). Patients were the most adherent to non-steroidal anti-inflammatory/acetaminophen orders at T(1) (2.91) and medications for neuropathic pain at T(2) (2.89). Data provided statistical evidence that patients with more hours of controlled pain in the past 24 hours were more likely to have had better adherence, whereas patients with higher levels of comfort over the last few days were more likely to have had worse adherence. CONCLUSION: This study identified that pain medication adherence among older adults with cancer receiving hospice care is high. However, hospices must be alert to the fact that even as patients become more comfortable, adherence must continue to be emphasized to ensure that pain does not redevelop or exacerbate, if pain relief is a patient priority.

**SYMPTOM CONTROL**

PPC/2014/Symp 1

**Lack of energy: An important and distinct component of HIV-related fatigue and daytime function**

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*J Pain Symptom Manage.* 2013;45(2):191–201

CONTEXT: Fatigue is a prevalent symptom among adults living with human immunodeficiency virus (HIV). There is increasing evidence that fatigue and...
energy are related, yet distinct constructs. Although HIV-related fatigue has been well studied, little is known about perceived energy and how it relates to fatigue, individual characteristics, and other symptoms. OBJECTIVES: To describe the experience of perceived energy in adults with HIV and evaluate its relationship to demographic and clinical characteristics as well as symptoms of fatigue, sleep disturbances, anxiety, depression, and daytime function. METHODS: The design was descriptive, comparative, and correlational. The sample of 318 adults with HIV completed a demographic questionnaire; the Memorial Symptom Assessment Scale; and measures of fatigue, sleep disturbance, anxiety, depressive symptoms, and daytime function. Medical records were reviewed for disease and treatment data. Participants who reported a lack of energy were compared with those who did not on demographic, clinical, and symptom variables. Regression models of perceived energy and its interference with daytime function also were evaluated. RESULTS: Perceived lack of energy was highly prevalent (65%) and more strongly related to interference with daytime function than more general measures of fatigue severity, even when controlling for other characteristics and symptoms. Like other aspects of fatigue, lack of energy was associated with sleep disturbance, anxiety, and depressive symptoms. Lack of energy was more strongly related to morning fatigue than to evening fatigue. CONCLUSION: Lack of energy interferes with daytime function and is not just the inverse of fatigue but a distinct perception that differs from fatigue.

PPC/2014/Sym 2
Constipation in palliative care: What do we use as definitions and outcome measures?
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J Pain Symptom Manage. 2013;45(4):753–62

CONTEXT: Advances in the management of constipation in palliative care remain hindered by the lack of agreed-upon diagnostic criteria. OBJECTIVES: The objective of this work was to emphasize this issue by systematically examining the eligibility and primary outcome measures in studies of constipation in the hospice and palliative care population. METHODS: A palliative care-specific electronic literature search was undertaken using the validated domain filter ‘palliative care’ and topic filter ‘constipation’ in CareSearch (www.caresearch.com.au), which interrogates PubMed in real time (1965–2011). Studies were included if they were primary reports of the treatment of constipation in a palliative care setting. Articles could be prospective or retrospective; randomized controlled trials, cohort studies, or case series. RESULTS: Twenty articles on the palliative care population were included in which there were six different definitions of constipation. Only 12 of 20 articles used their cited definitions of constipation as the studies’ primary outcome measures and 4 of 4 blinded, randomized controlled trials. Articles that used the time between bowel actions or the use of laxatives as the definition of constipation were most likely to report outcomes based on these criteria. CONCLUSION: Constipation is a significant problem in palliative care; however, not having an agreed-upon definition limits research initiatives and the ability to apply these results clinically to people with constipation. Four domains are suggested as pivotal to the diagnosis: any life-long history of constipation (using the Rome Criteria), evaluation of physical changes that may cause or worsen constipation, the subjective sensation (such as feelings of incomplete defecation or bloating or fullness), and objective changes (such as frequency or consistency of stools).

PPC/2014/Sym 3
The effect of severe androgen deficiency on physical function in male patients with cancer
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J Pain Symptom Manage. 2013;45(5):892–900

CONTEXT: Low circulating testosterone concentrations are commonly observed in male patients with cancer and have been shown to be associated with weight loss and increased severity of many symptoms, including fatigue and weakness. OBJECTIVES: The aim of the present study was to determine the extent to which testosterone deficiency is associated with poor physical function in male patients with non-hormonal cancers. METHODS: We measured serum-free testosterone concentration in 101 male patients with cancer evaluated at a nutrition-rehabilitation clinic and performed univariate and multivariate linear regression analyses to assess the effect of a free testosterone concentration in the lowest quartile on 6-minute walk distance (6-MWD) (n = 100) and maximal gait speed (n = 49). RESULTS: In the univariate analyses, patients in the lowest free testosterone quartile had a 6-MWD that was 96 m (95% confidence interval (CI) 51, 141) less and a maximal gait speed that was 0.26 m/second (95% CI 0.06, 0.47) slower on average than patients in the upper three free testosterone quartiles. When controlling for other demographic, clinical, and biological factors, a free testosterone concentration in the lowest quartile was associated, on average, with a 51 m (95% CI 44, 97) lower 6-MWD but did not affect maximal gait speed. CONCLUSION: The present study shows that in male patients with cancer, an extremely low serum-free testosterone concentration is independently
associated with 6-MWD but not maximal gait speed. Hence, a severe testosterone deficiency may impair their ability to perform sustained activity, but to a lesser degree, short bursts of activity.

**PPC/2014/Symp 4**

Management of moderate-to-severe dyspnea in hospitalized patients receiving palliative care

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*J Pain Symptom Manage*. 2013;45(5):885–91

**CONTEXT:** Benzodiazepines (BZDs) are commonly prescribed for relief of dyspnea in palliative care, yet few data describe their efficacy. **OBJECTIVES:** To describe the management of moderate-to-severe dyspnea in palliative care patients. **METHODS:** Chart review of inpatients with moderate or severe dyspnea on initial evaluation by a palliative care service. We recorded dyspnea scores at follow-up (24 hours later) and use of BZDs and opioids. **RESULTS:** The records of 115 patients were reviewed. The mean age of patients was 64 years and primary diagnoses included cancer (64%, \( n = 73 \)), heart failure (8%, \( n = 9 \)), and chronic obstructive pulmonary disease (5%, \( n = 6 \)). At initial assessment, 73% (\( n = 84 \)) of the patients had moderate and 27% (\( n = 31 \)) had severe dyspnea. At follow-up, 74% (\( n = 85 \)) of patients reported an improvement in their dyspnea, of which 42% (\( n = 36 \)) had received opioids alone, 37% (\( n = 31 \)) had BZDs concurrent with opioids, 2% (\( n = 2 \)) had BZDs alone, and 19% (\( n = 16 \)) had received neither opioids nor BZDs. Logistic regression analysis identified that patients who received BZDs and opioids had increased odds of improved dyspnea (odds ratio 5.5, 95% confidence interval 1.4, 21.3) compared with those receiving no medications. **CONCLUSION:** Most patients reported improvement in dyspnea at 24 hours after palliative care service consultation. Consistent with existing evidence, most patients with dyspnea received opioids but only the combination of opioids and BZDs was independently associated with improvement in dyspnea. Further research on the role of BZDs alone and in combination with opioids may lead to better treatments for this distressing symptom.

**PPC/2014/Symp 5**

Randomized double-blind trial of sublingual atropine vs. placebo for the management of death rattle

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*J Pain Symptom Manage*. 2013;45(1):14–22

**CONTEXT:** Noisy breathing because of respiratory tract secretions (RTS), often referred to as ‘death rattle’, occurs in up to half of all dying patients. Despite a lack of evidence showing benefit compared with placebo, antimuscarinic medications have been used in an attempt to decrease noise associated with RTS and to decrease family distress. **OBJECTIVES:** The goal of this study was to compare the efficacy of the antimuscarinic medication atropine with that of placebo in reducing noise associated with death rattle. **METHODS:** Terminally ill adult hospice inpatients who developed noisy breathing as a result of RTS were randomized to double-blind treatment with atropine or placebo. Study drug was given as a single sublingual dose. Noise from breathing was monitored at baseline and at 2 and 4 hours. **RESULTS:** One hundred and thirty-seven participants were randomized to atropine or placebo. Reduction in noise score from baseline to 2 hours after dose occurred in 37.8 and 41.3% of subjects treated with atropine and placebo, respectively (\( P = 0.73 \)). Noise score reduction at 4 hours occurred in 39.7 and 51.7% of subjects treated with atropine and placebo, respectively (\( P = 0.21 \)). Differences between groups were not significant at either timepoint. Atropine was well tolerated. Heart rate increased slightly in both groups (+1.1/minute for atropine and +3.1/minute for placebo) but not significantly. **CONCLUSION:** Sublingual atropine given as a single dose was not more effective than placebo in reducing the noise associated with death rattle.

**PPC/2014/Symp 6**

Clarifying delirium management: Practical, evidenced-based, expert recommendations for clinical practice

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Delirium is highly prevalent in those with serious or advanced medical illnesses. It is associated with many adverse consequences, including significant patient, family, and healthcare provider distress. This article suggests a novel approach to delirium assessment and management and provides useful, practical guidance for clinicians based on a complete review of the existing literature and the expert clinical opinion of the authors and their colleagues, derived from over a decade of collective bedside experience. Comprehensive assessment includes careful description of observed symptoms, signs, and behaviors; and an understanding of the patient’s situation, including primary diagnosis, associated comorbidities, functional status, and prognosis. The importance of incorporating goals of care for the patient and family is discussed. The concepts of potential reversibility versus irreversible delirium and delirium subtype are proffered, with a description of how diagnostic and
management strategies follow from these concepts. Pharmacological interventions that provide rapid, effective, and safe relief are presented. Employing both pharmacological and non-pharmacological interventions, including patient and family education, improves symptoms and relieves patient and family distress, whether the delirium is reversible or irreversible, hyperactive or hypoactive. All interventions can be provided in any setting of care, including patients’ homes.

**PPC/2014/Symp 7**

**The evidence base for oxygen for chronic refractory breathlessness: Issues, gaps, and a future work plan**

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*J Pain Symptom Manage.* 2013;45(4):763–75

Breathlessness or ‘shortness of breath,’ medically termed dyspnea, is a common and distressing symptom featuring strongly in advanced lung, cardiac, and neuromuscular diseases; its prevalence and intensity increase as death approaches. However, despite the increasing understanding in the genesis of breathlessness, as well as an increasing portfolio of treatment options, breathlessness is still difficult to manage and engenders helplessness in caregivers and healthcare professionals and fear for patients. Although hypoxemia does not appear to be the dominant driver for breathlessness in advanced disease, the belief that oxygen is important for the relief of acute, chronic, and acute-on-chronic shortness of breath is firmly embedded in the minds of patients, caregivers, and healthcare professionals. This article presents current understanding of the use of oxygen for treating refractory breathlessness in advanced disease. The objective is to highlight what is still unknown, set a research agenda to resolve these questions, and highlight methodological issues for consideration in planned studies.

**PPC/2014/Symp 8**

**Sleep and sleep–wake disturbances in care recipient–caregiver dyads in the context of a chronic illness: A critical review of the literature**

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*J Pain Symptom Manage.* 2013;45(3):579–94

**CONTEXT:** Alterations in sleep–wake patterns of care recipients and their informal caregivers are common in the context of a chronic illness. Given the current notion that sleep may be regulated within and affected by close human relationships, concurrent and interrelated sleep problems may be present in care recipient–caregiver dyads. **OBJECTIVES:** To critically analyze evidence regarding concurrent sleep patterns or changes in care recipient–caregiver dyads in the context of a chronic illness and address methodological and research gaps. **METHODS:** Using a wide range of key terms and synonyms, three electronic databases (Medline, CINAHL, and Embase) were systematically searched for the period between January 1990 and July 2011. **RESULTS:** Ten studies met pre-specified selection criteria and were included for analysis. Study quality was fair to good on average. Seven studies were conducted in the context of dementia or Parkinson’s disease, two in the context of cancer, and one study included a group of community elders with mixed related comorbidities and their informal caregivers. Bidirectional associations in the sleep of care recipient–caregiver dyads seem to exist. Concurrent and comparable nocturnal sleep disruptions also may be evident. Yet, inconsistencies in the methods implemented, and the samples included, as well as uncertainty regarding factors co-affecting sleep, still preclude safe conclusions to be drawn on. **CONCLUSION:** The dyadic investigation of sleep is a promising approach to the development of truly effective interventions to improve sleep quality of care recipients and their caregivers. Nevertheless, more systematic, longitudinal dyadic research is warranted to augment our understanding of co-occurrence and over time changes of sleep problems in care recipient–caregiver dyads, as well as to clarify covariates/factors that appear to contribute to these problems within the dyad and across time and context of illness.

**PPC/2014/Symp 9**

**An integrative review of sexual health issues in advanced incurable disease**

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*J Palliat Med.* 2013;16(6):686–91

The sexual health needs of people with advanced incurable diseases are underexplored and understudied by healthcare practitioners and understudied by researchers. The loss of sexual health can impact a person’s overall quality of life and well-being. This integrative review of the literature presents the current state of the science and was conducted to identify and summarize publications in the professional literature related to the sexual health needs of people with advanced illness. A systematic search of 18 databases for studies conducted between 1960 and April 2012 in the English language that focused on the sexual health needs of people with life-limiting illnesses was conducted. Findings document that studies regarding the sexual health of patients with life-limiting illnesses are generally narrative reviews,
expert opinions, or exploratory in nature. Of the 30 possibly relevant abstracts and titles identified, there was only one prospective or case control trial focusing on sexual health in this population thereby offering the practitioner little research evidence to inform clinical practice. Increasing our understanding of the sexual health needs of people facing the end of their lives is crucial if we are to conduct appropriate assessments and initiate relevant treatments. Further prospective research is required to assess and establish the sexual health concerns of people along the disease trajectory of incurable illness as well as those imminently facing the end of their lives.

**PPC/2014/Symp 10**

**The identification of plasma proteins associated with cancer-related fatigue syndrome (CRFS) in disease-free breast cancer patients using proteomic analysis**

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*J Pain Symptom Manage. 2013;45(5):868–74*

**CONTEXT:** Cancer-related fatigue syndrome (CRFS) affects a significant minority of women successfully treated for breast cancer, with symptoms lasting up to several years after finishing therapy. **OBJECTIVES:** This analysis was conducted to identify plasma proteins associated with CRFS in disease-free breast cancer patients. **METHODS:** Women were divided into those meeting the CRFS criteria (cases) and a control group on the basis of a diagnostic interview. Plasma samples were collected from 45 cases and 45 controls. Proteomic analysis was conducted using surface-enhanced laser desorption/ionization, a mass spectrometry (MS) technique. This was followed by further sample processing using one-dimensional gels and trypsin digest for protein identification using liquid chromatography and database searching. **RESULTS:** CRFS was associated with a statistically significant increase in the intensity of seven MS spectra. A subsequent search of proteins corresponding to the MS spectra identified four acute phase proteins associated with a non-specific immune response (serum amyloid A, collectin, and subunits of immunoglobulin G and complement C1Q). **CONCLUSION:** These novel results (using a technique not previously used in fatigue research) add further weight to the hypothesis that CRFS may be precipitated and prolonged by a non-specific sustained inflammatory response. Importantly, this has been identified from a global analysis of plasma, which was conducted with no prior assumptions. Although these results need confirmation, we would suggest that future treatments for CRFS should consider focusing on the modulation of this presumed prolonged immune response.

**PPC/2014/Symp 11**

**Bupropion for control of hot flashes in breast cancer survivors: A prospective, double-blind, randomized, crossover, pilot phase II trial**

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*J Pain Symptom Manage. 2013;45(6):969–79*

**CONTEXT:** Hot flashes (HFs) and sexual dysfunction often affect breast cancer (BC) survivors and compromise their quality of life. Bupropion is an antidepressive medication used for smoking cessation and also has been previously studied for the treatment of sexual dysfunction. **OBJECTIVES:** We aimed to evaluate bupropion’s efficacy in controlling HFs in BC survivors. **METHODS:** This was a randomized, double-blind, crossover, placebo-controlled pilot study that enrolled 55 BC survivors who reported more than 7 HFs per week. Subjects were randomized to receive either bupropion 150 mg twice daily for 4 weeks followed by 1 week of washout and four more weeks of placebo twice daily or vice versa. The primary endpoint was average daily HF activity (number of HFs and a score combining number and severity) reported while on bupropion or on placebo. Secondary endpoints were sexual dysfunction, depression, and quality of life evaluated with the Arizona Sexual Experience Scale, Beck Depression Inventory, and European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30, respectively. **RESULTS:** Bupropion reduced HFs by 1.26 per day and the HF score by 6.31%, whereas placebo reduced HFs by 2.11 per day (P > 0.05) and the HF score by 30.47% (P > 0.05). There were no statistically significant differences between bupropion and placebo in the Arizona Sexual Experience Scale, Beck Depression Inventory, and European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30. At the end of the study, 47% of the patients preferred bupropion, whereas 53% preferred placebo. There were no statistically significant differences in side effects between the study groups. **CONCLUSION:** Compared with placebo, bupropion did not control HFs in this group of BC survivors.

**PPC/2014/Symp 12**

**Olanzapine: Palliative medicine update**

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*Am J Hosp Palliat Med. 2013;30(1):75–82*

Olanzapine is an atypical antipsychotic agent of the thienobenzodiazepine class. Olanzapine blocks multiple neurotransmitter receptors, including dopaminergic (D(1), D(2), D(3), and D(4)), serotonergic (5-hydroxytryptamine 2A (5-HT(2A)), 5-HT(2C), 5-HT(3), and...
5-HT(6), adrenergic (alpha(1)), histaminic (H(1)), and muscarinic (M(1), M(2), M(3), and M(4)) receptors. Olanzapine has a high affinity for the 5-HT(2A) receptor, which is up to five times greater than the dopamine receptor, resulting in less propensity to the development of extrapyramidal side effects. The affinity of olanzapine for multiple receptors has led to the identification of olanzapine as an important agent in the treatment of delirium, nausea, and vomiting. Olanzapine has been demonstrated to have opioid-sparing properties. Olanzapine is principally metabolized by glucuronidation, with a smaller metabolic contribution from the cytochrome oxidase system. Adverse effects of olanzapine include somnolence, postural hypotension, constipation, dizziness, restlessness, and weight gain. The purpose of this article is to outline the pharmacodynamics, pharmacology, and evidence for the use of olanzapine in palliative care.

**PPC/2014/Symp 13**

**Use of pregabalin in the management of chronic uremic pruritus**

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*J Pain Symptom Manage.* 2013;45(4):776–81

**CONTEXT:** Uremic pruritus (UP) affects many patients suffering from chronic kidney disease (CKD) and has a negative impact on quality of life and survival. It has become increasingly evident that central transmission and sensitization processes similar to those observed in chronic pain are important mechanisms of pruritus. **OBJECTIVES:** To test the potential role of pregabalin in reducing the intensity of UP in CKD patients. **METHODS:** We prospectively collected data on CKD patients who suffered from severe intractable pruritus. Patients were asked to record the intensity of pruritus on a visual analog scale. **RESULTS:** Twelve patients were studied. The average pretreatment pruritus score was 9.7 ± 0.9 and decreased to 3.7 ± 2.35, 3.2 ± 1.75, and 3 ± 1.5 after 1, 4, and 24 weeks of treatment, respectively ($P < 0.05$). The positive effect of pregabalin was demonstrated during the first week of therapy in six patients. Most patients required 25 mg a day. Pregabalin was well tolerated, with somnolence and dizziness developing in two patients. **CONCLUSION:** We demonstrated dramatic improvement of long-standing UP after the initiation of pregabalin. We suggest that pregabalin can be used safely in CKD but careful titration of the dose is required to obtain an optimal response and minimize the possible adverse effects.

**PPC/2014/Symp 14**

**Episodic and continuous breathlessness: A new categorization of breathlessness**

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*J Pain Symptom Manage.* 2013;45(6):1019–29

**CONTEXT:** Unlike pain, where the concept of breakthrough and background pain has been widely characterized and defined, breathlessness as a symptom has not yet been fully explored and has been rarely categorized. **OBJECTIVES:** To test patients’ experiences and descriptions of breathlessness to categorize breathlessness. **METHODS:** Qualitative study using in-depth interviews with patients suffering from four life-limiting and advanced diseases (chronic heart failure, chronic obstructive pulmonary disease, lung cancer, and motor neuron disease). Interviews were tape-recorded, transcribed verbatim, and analyzed using Framework analysis. **RESULTS:** A total of 51 participants were interviewed (mean ± SD age 68.2 ± 11.6 years; 30 of 51 male; median Karnofsky 60%; mean ± SD breathlessness intensity 3.2 ± 1.7 of 10). Episodic breathlessness and continuous breathlessness were the main categories, with subcategories of triggered and non-triggered episodic breathlessness and continuous breathlessness for short and long periods. Episodic breathlessness triggered by exertion, non-triggered episodic breathlessness, and continuous breathlessness for a long period (‘constant variable’) were the most frequent and important categories with a high impact on daily living. Exertional breathlessness occurred in nearly all participants. Participants could differentiate episodic breathlessness (seconds, minutes, or hours) and continuous breathlessness (days, weeks, or months) by time. Episodic breathlessness occurred in isolation or in conjunction with continuous breathlessness. **CONCLUSION:** Participants categorize their breathlessness by time and triggers. The categorization needs further verification, similar to that already established in pain, and can be used as a new evidence-based categorization to advance our understanding of this underresearched, yet high impact, symptom to optimize management.

**PPC/2014/Symp 15**

**Randomized, double-blind, placebo-controlled trial of oral docusate in the management of constipation in hospice patients**

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*J Pain Symptom Manage.* 2013;45(1):2–13

**CONTEXT:** The stool softener docusate is widely used in the management of constipation in hospice patients. There is little experimental evidence to support this practice, and no randomized trials have been conducted in the hospice setting. **OBJECTIVES:** To assess the efficacy of docusate in hospice patients. **METHODS:** This was a 10-day,
prospective, randomized, double-blind, placebo-controlled trial of docusate and sennosides vs. placebo and sennosides in hospice patients in Edmonton, Alberta. Patients were included if they were age 18 years or older, able to take oral medications, did not have a gastrointestinal stoma, and had a Palliative Performance Scale score of 20% or more. The primary outcome measures were stool frequency, volume, and consistency. Secondary outcomes were patient perceptions of bowel movements (difficulty and completeness of evacuation) and bowel-related interventions. RESULTS: A total of 74 patients were randomized into the study (35 to the docusate group and 39 to the placebo group). There were neither significant differences between the groups in stool frequency, volume, or consistency, nor in difficulty or completeness of evacuation. On the Bristol Stool Form Scale, more patients in the placebo group had Type 4 (smooth and soft) and Type 5 (soft blobs) stool, whereas in the docusate group, more had Type 3 (sausage-like) and Type 6 (mushy) stool ($P = 0.01$). CONCLUSION: There was no significant benefit of docusate plus sennosides compared with placebo plus sennosides in managing constipation in hospice patients. Docusate use should be considered on an individual basis.

PPC/2014/Symp 16

Characteristics of advanced cancer patients with cancer-related fatigue enrolled in clinical trials and patients referred to outpatient palliative care clinics

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J Pain Symptom Manage. 2013;45(3):534–41

CONTEXT: Limited published data exist on whether characteristics of patients with advanced cancer enrolled in cancer-related fatigue clinical trials (CCTs) differ from patients in outpatient palliative care clinics (OPCs). OBJECTIVES: The primary aim of this study was to compare the characteristics of two groups of patients with advanced cancer and moderate-to-severe fatigue: patients in CCTs and patients at an OPC. METHODS: We retrospectively reviewed the records of 337 patients who were enrolled in one of five CCTs for advanced cancer patients at the University of Texas MD Anderson Cancer Center as well as the records of 1896 consecutive patients who were referred to our OPC from January 2003 through December 2010. Patients with fatigue scores of $>4/10$ (measured by the Edmonton Symptom Assessment System (ESAS)) were eligible (1252 OPC patients and 337 CCT patients). Patient characteristics, ESAS scores, and survival times were compared using Chi-square tests, Wilcoxon rank-sum tests, and the Kaplan-Meier method.

RESULTS: Compared with the CCT patients, OPC patients were more likely to be older (58 vs. 59 years; $P = 0.009$) and male (38 vs. 52%; $P < 0.001$). The most common primary cancer type was breast cancer (22%) in the CCT patients and lung cancer (23%) in the OPC patients ($P < 0.001$). The median ESAS scores in the OPC and CCT groups, respectively, were 6 and 4 for pain ($P < 0.001$), 7 and 7 for fatigue ($P = 0.525$), 3 and 2 for depression ($P = 0.004$), 3 and 2 for anxiety ($P < 0.001$), 3 and 2 for dyspnea ($P < 0.001$), and 43 and 32 for the symptom distress score ($P < 0.001$). The median overall survival times were 17.9 months (95% confidence interval (CI) 13.5–22.3 months) in the CCT group and 3.8 months (95% CI 3.5–4.1 months) in the OPC group ($P < 0.001$). CONCLUSION: Baseline characteristics and overall survival times significantly differed between patients enrolled in the CCT and OPC groups. Therefore, we conclude that the results of CCTs cannot be generalized to patients being treated in OPCs.

QUALITY OF LIFE

PPC/2014/Qol 1

Does health status affect perceptions of factors influencing dignity at the end of life?

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J Pain Symptom Manage. 2013;45(6):1030–8

CONTEXT: More people are surviving into old age, and chronic diseases tend to become more common with age. Ill health and disability can lead to concerns about loss of personal dignity. OBJECTIVES: To investigate whether health status affects the perceptions of factors influencing personal dignity at the end of life, and the relationship between those perceptions and sociodemographic characteristics. METHODS: A subsample ($n = 2282$) of a large advance directives cohort study was used. Three different health status groups (good, moderate, and poor) were defined based on the Euroqol-5D and a question on whether they had an illness. For each health status group, we calculated the percentage of respondents who indicated the extent to which the items of the Patient Dignity Inventory would influence their dignity as (very) large. Logistic regression analyses were used to investigate the associations between the perceptions of factors influencing personal dignity and sociodemographics. RESULTS: The percentage of respondents who indicated the factors as having a (very) large influence on dignity at the end of life were not significantly different for the three health
status groups, except for three physical items on symptoms, roles, and routines. Those items were significantly more influential on dignity for people with a poor health status. Gender, old age, having a partner, and having a belief or religion that is important to one’s life were associated with an understanding of factors influential to dignity. CONCLUSION: Health status seems only to affect the perceptions of physical factors maintaining dignity at the end of life. This might suggest that the understanding of dignity will not substantially change as health status changes and may support starting advance care planning early.

**Interventions to improve symptoms and quality of life of patients with fibrotic interstitial lung disease: A systematic review of the literature**

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Thorax. 2013;68(9):867–79

**BACKGROUND:** Patients with fibrotic interstitial lung disease have symptom control and quality of life (QoL) needs. This review aims to evaluate the evidence for the use of interventions in improving dyspnoea, other symptoms, and QoL. METHODS: Eleven databases, relevant websites, and key journals were hand-searched. Studies were assessed and data extracted independently by two researchers using standardized proformas. Meta-analyses were performed where possible with 95% confidence interval (CI). RESULTS: Thirty-four papers with 19 interventions in 3635 patients were included. Meta-analyses showed no significant effect of interferon-1b or sildenafil on 6-minute walking distance (6MWD) or dyspnoea. Pulmonary rehabilitation and pirfenidone had a positive effect on 6MWD (mean difference (95% CI) 27.4 (4.1–50.7) and 24.0 (4.3–43.7), respectively), and pulmonary rehabilitation had a mixed effect on dyspnoea. Both pulmonary rehabilitation and sildenafil showed a trend towards significance in improving QoL. There was weak evidence for the improvement of 6MWD using oxygen; dyspnoea using prednisolone, diamphamine, d-pencillamine, and colchicine; cough using interferon alpha and thalidomide; anxiety using diamphamine; fatigue using pulmonary rehabilitation; and QoL using thalidomide and doxycycline. A wide range of outcome scales was used and there were no studies with economic evaluation. CONCLUSIONS: There is strong evidence for the use of pulmonary rehabilitation and pirfenidone to improve 6MWD and moderate evidence for the use of sildenafil and pulmonary rehabilitation to improve QoL. Future recommendations for research would include careful consideration of the dichotomy of radical and palliative treatments when deciding on how symptom and QoL outcome measures are used and data presented.

**Association between body image dissatisfaction and weight loss among patients with advanced cancer and their caregivers: A preliminary report**

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**CONTEXT:** No prospective studies have dealt with the impact of cachexia-related weight loss on patients’ body image as well as the impact of patients’ body image changes on the level of patient and family distress. **OBJECTIVES:** Our aim was to examine associations between body mass index (BMI), weight loss, symptom distress, and body image for patients with advanced cancer and their caregivers. METHODS: Outpatients with advanced cancer and different levels of BMI, along with their caregivers, were recruited. Patient assessments included BMI, pre-cancer weight, Body Image Scale (BIS; 0–30), Edmonton Symptom Assessment System (ESAS), Hospital Anxiety and Depression Scale (HADS), and sexual interest and enjoyment as measured by the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Head and Neck Cancer Module 35. Caregivers were asked to assess the patient’s body image, using the BIS; rate their own quality of life, using the Caregiver Quality of Life Index-Cancer; and rate their overall distress and distress regarding the patient’s weight, using the Distress Thermometer (DT). RESULTS: We included 81 patients and 30 caregivers. Forty-eight patients (59%) experienced weight loss of at least 10%. The mean BIS score was 11.23 (SD = 7.24). Body image dissatisfaction was correlated with weight loss (r = 0.31, P = 0.006), anxiety (HADS-A; r = 0.39, P < 0.001), depression (HADS-D; r = 0.46, P < 0.001), decreased sexual interest (r = 0.37, P = 0.001), decreased sexual enjoyment (r = 0.33, P = 0.004), ESAS score for pain (r = 0.25, P = 0.036), fatigue (r = 0.52, P = 0.014), drowsiness (r = 0.28, P = 0.014), shortness of breath (r = 0.27, P = 0.016), sleep disorders (r = 0.24, P = 0.036), and well-being (r = 0.29, P = 0.011). We found a significant association between the caregivers’ evaluation of patients’ body image dissatisfaction and patients’ BIS score (r = 0.37, P = 0.049) and caregivers’ distress regarding the patients’ weight (DT; r = 0.58; P = 0.001). CONCLUSION: Body image dissatisfaction was strongly associated with patients’ weight loss and with psychosocial distress among...
patients and their caregivers. More research is necessary to better understand the association between the severity of body image dissatisfaction and the severity of other problems in patients with cancer.

**PPC/2014/Qol 4**

**Comfort measures only: Agreeing on a common definition through a survey**

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*Am J Hosp Palliat Med. 2013;30(1):35–9*

Despite how frequently we say ‘comfort measures only’ (CMO) in the hospital setting, review of the medical literature yields poor representation and definition of the term. Through a survey in our hospital center, we aimed at understanding what doctors understand as CMO. A total of 176 physicians responded to the survey. We asked them about the moment in the patient care timeline when to use it and what degree of respiratory support, laboratory draws, antibiotic therapy, level of care, and code status should be a part of it. Disparities in responses were the norm, and common defining characteristics were the exception.

**PSYCHOSOCIAL ISSUES**

**PPC/2014/Psych 1**

**Prevalence and risk factors of depressive symptoms in a Canadian palliative home care population: A cross-sectional study**

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*BMC Palliat Care. 2014;13(1):10*

**BACKGROUND:** Depression in palliative care patients is important because of its intrinsic burden and association with elevated physical symptoms, reduced immunity, and increased mortality risk. Identifying risk factors associated with depression can enable clinicians to more readily diagnose it, which is important since depression is treatable. The purpose of this cross-sectional study was to determine the prevalence of depressive symptoms and risk factors associated with them in a large sample of palliative home care patients. **OBJECTIVES:** To examine the results of the complete case and multiple imputation analyses, and found them to be similar. **RESULTS:** The prevalence of depressive symptoms was 9.8%. The risk factors associated with depressive symptoms were (pooled estimates, multiple imputation): low life satisfaction (odds ratio = 3.01 (confidence interval = 2.37–3.82)), severe and moderate sleep disorders (2.56 (2.05–3.19) and 1.56 (1.18–2.06)), health instability (2.12 (1.42–3.18)), caregiver distress (2.01 (1.62–2.51)), daily pain (1.73 (1.35–2.22)), cognitive impairment (1.45 (1.13–1.87)), being female (1.37 (1.11–1.68)), and gastrointestinal symptoms (1.27 (1.03–1.55)). Life satisfaction mediated the effect of prognostic awareness on depressive symptoms.

**CONCLUSIONS:** The prevalence of depressive symptoms in our study was close to the median of 10–20% reported in the palliative care literature, suggesting that they are present but by no means inevitable in palliative patients. Most of the factors associated with depressive symptoms in our study are amenable to clinical intervention and often targeted in palliative care programs. Designing interventions to address them can be challenging, however, requiring careful attention to patient preferences, the spectrum of comorbid conditions they face, and their social supports. Life satisfaction was one of the strongest factors associated with depressive symptoms in our study, and is likely to be among the most challenging to address.

**PPC/2014/Psych 2**

**Minor cognitive impairments in cancer patients magnify the effect of caregiver preferences on end-of-life care**

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*J Pain Symptom Manage. 2013;45(4):650–9*

**CONTEXT:** Cognitive impairment commonly affects cancer patients. **OBJECTIVES:** To examine whether minor cognitive impairment in patients with advanced cancer is associated with the intensity of end-of-life (EOL) care or modifies the influence of patient and caregiver preferences on the intensity of EOL care. **METHODS:** Data were derived from structured interviews with 221 advanced cancer patient–caregiver dyads in the Coping with Cancer Study, a multisite, longitudinal cohort study. Deficits in patients’ cognitive function were identified using the Short Portable Mental Status Questionnaire (SPMSQ). Patients and caregivers reported preferences regarding life-extending vs. symptom-directed care. Information regarding EOL care was obtained from postmortem interviews with caregivers. Logistic regression analyses modeled main and interactive effects of patients’ cognitive
impairment and patients’ and caregivers’ treatment preferences on intensive EOL care. RESULTS: Cognitive impairment was associated with less intensive EOL care (odds ratio (OR) = 0.56; 95% confidence interval (CI): 0.34–0.91). Patients and caregivers had poor agreement regarding preferences for life-extending vs. symptom-directed care (0.10; \( \chi^2 = 2.32, df = 1, P = 0.13 \)). Patient preference for life-extending care predicted intensive EOL care irrespective of cognitive status (adjusted odds ratio (AOR) = 2.11; 95% CI: 1.04–4.28). For patients with no errors on the SPMSQ, caregiver preference for life-extending care was unrelated to intensive EOL care (AOR = 0.40; 95% CI: 0.09–1.77). However, the association between caregiver preference for life-extending care and intensive EOL care increased by nearly a factor of seven for every error on the SPMSQ (interaction AOR = 6.90; 95% CI: 1.40–34.12). CONCLUSION: Cognitive impairment in patients with advanced cancer is associated with less intensive EOL care. Caregivers’ influence on intensive EOL care dramatically increases with minor declines in patients’ cognitive function.

PPC/2014/Psych 3

Barriers to the detection and management of depression by palliative care professional carers among their patients: Perspectives from professional carers and patients’ family members

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INTRODUCTION: Clinical depression is highly prevalent yet underdetected and poorly managed within palliative care settings. OBJECTIVES: This qualitative study explored the identification, monitoring, and management of symptoms of depression in patients receiving palliative care from two juxtaposed perspectives that are of care providers and care recipients’ family members. Examining the barriers that restrict professional carers, detecting and managing depression in their patients was a central focus of the study. METHODS: Focus groups were held with 18 professional carers, including 8 holding managerial positions, across 2 palliative care services, 1 regional and 1 metropolitan, which provided both inpatient and community-based care. Individual interviews were conducted with 10 family members of patients who had received or were receiving palliative care through these services. RESULTS: Thematic analysis of these data identified that both professional carers and family members perceived that depression is a wide-spread concern for patients receiving palliative care; however, numerous barriers were identified that affect professional carers’ ability to identify depression. These included knowledge and training deficits, low self-efficacy, prioritization of physical concerns and time constraints, patient/family characteristics, and system/process issues. These themes (and related subthemes) are discussed in this article. CONCLUSIONS: Specialized training in depression is recommended for professional carers in order to improve their depression-related knowledge, detection skills, and self-efficacy. The ultimate goal of such training is to increase the rate of recognition of depression that in turn will lead to appropriate treatment for depressed patients.

PPC/2014/Psych 4

Cultural differences in spiritual care: Findings of an Israeli oncologic questionnaire examining patient interest in spiritual care

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BMC Palliat Care. 2014;13(1):19

BACKGROUND: As professional spiritual care (chaplaincy) is introduced to new cultures worldwide, it bears examining which elements of screening and care are universal and, for those elements showing cultural difference, to study them in each culture. No quantitative spiritual care patient study had previously been done in Israel. Our objectives were twofold: (1) to examine who wants spiritual care in Israel, including demographic and clinical variables, and to compare against other results worldwide to further develop universal screening protocols; (2) to see what patients want from spiritual care specifically in the Israeli setting. METHODS: Self-administered patient questionnaire examining spirituality/religiosity, interest in spiritual care (subdivided by type of care), and key demographic, social, and clinical data. The study setting was an Israeli oncology center at which spiritual care had been recently introduced. RESULTS: Data from 364 oncology patient questionnaires found 41% interest in spiritual care, as compared to 35–54% in American studies. Having previously been visited by a spiritual caregiver predicted patient interest in further spiritual care (adjusted odds ratio (AOR) 2.4, 95% confidence interval (CI) 1.2–4.6), suggesting that the new service is being well-received. Multivariate stepwise logistic regression analysis identified additional predictors of openness to receiving spiritual care: self-describing as somewhat/very spiritual vs. not spiritual (AOR 3.9 and 6.3, 95% CI 1.8–8.6 and 2.6–15.1) or traditional/religious vs. secular (AOR 2.2 and 2.1, 95% CI 1.3–3.6 and 1.1–4.0); and receiving one visit a week or less from family and friends (AOR 5.6, 95% CI 2.1–15.1). These findings are in line with previous American studies, suggesting universality across cultures that could be utilized in screening. Differences in demographic data and medical condition were not significant predictors of patient interest, suggesting a
cultural difference, where age and education were predictors in the American context. Levels of interest in explicitly religious or spiritual support such as prayer or addressing religious/spiritual questions were much lower than in other cultures. CONCLUSIONS: Results illustrate the demand for and satisfaction with the new Israeli service. The cross-cultural comparison found both culture-dependent and possibly universal predictors of patient interest, and found lower interest in Israel for explicitly religious/spiritual types of support.

DEATH

PPC/2014/Death 1

Do patients with advanced cognitive impairment admitted to hospitals with higher rates of feeding tube insertion have improved survival?

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J Pain Symptom Manage. 2013;45(3):524–33

CONTEXT: Research is conflicting on whether receiving medical care at a hospital with more aggressive patterns of feeding improves survival. OBJECTIVES: The aim of this study was to examine whether nursing home residents admitted to hospitals with higher rates of feeding tube insertion had improved survival. METHODS: Using the 1999–2007 Minimum Data Set matched to Medicare claims, we identified hospitalized nursing home residents with advanced cognitive impairment who did not have a feeding tube inserted prior to their hospital admissions. The sample included 56,824 nursing home residents and 1773 acute care hospitals nationwide. Hospitals were categorized into nine groups based on feeding tube insertion rates and whether the rates were increasing, staying the same, or decreasing between the periods of 2000–2003 and 2004–2007. Multivariate logit models were used to examine the association between the hospital patterns of feeding tube insertion and survival among hospitalized nursing home residents with advanced cognitive impairment. RESULTS: Nearly one in five hospitals (N = 366) had persistently high rates of feeding tube insertion. Being admitted to these hospitals with persistently high rates of feeding tube insertion was not associated with improved survival when compared with being admitted to hospitals with persistently low rates of feeding tube insertion. The adjusted odds ratios were 0.93 (95% confidence interval (CI): 0.87, 1.01) and 1.02 (95% CI: 0.95, 1.09) for 1-month and 6-month post-hospitalization survival, respectively. CONCLUSION: Hospitals with more aggressive patterns of feeding tube insertion did not have improved survival for hospitalized nursing home residents with advanced cognitive impairment.

PPC/2014/Death 2

Oxygen is non-beneficial for most patients who are near death

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J Pain Symptom Manage. 2013;45(3):517–23

CONTEXT: Clinicians prescribe and administer oxygen in response to reports of dyspnea, in the face of dropping oxygen saturation, as a ‘routine’ comfort intervention, or to support anxious family members. Oxygen may produce nasal irritation and increase the cost of care. OBJECTIVES: To determine the benefit of administering oxygen to patients who are near death. METHODS: A double-blind, repeated-measure observation with the patient as his/her own control was conducted. The Respiratory Distress Observation Scale measured the presence and intensity of distress at baseline and at every gas or flow change. Medical air, oxygen, and no flow were randomly alternated every 10 minutes via nasal cannula with patients who were near death, at risk for respiratory distress, with no distress at the baseline of testing. Each patient had two encounters under each condition, yielding six encounters per patient. RESULTS: Patients were 66% female, 34% White, and 66% African American, and ages 56–97 years. Patients had heart failure (25%), chronic obstructive pulmonary disease (34%), pneumonia (41%), or lung cancer (9%). Most (91%) patients tolerated the protocol with no change in respiratory comfort. Three patients (9%) displayed distress and were restored to baseline oxygen; one patient died during the protocol while displaying no distress. Repeated-measure analysis of variance revealed no differences in the Respiratory Distress Observation Scale under changing gas and flow conditions. CONCLUSION: The routine application of oxygen to patients who are near death is not supported. The n-of-1 trial of oxygen in clinical practice is appropriate in the face of hypoxemic respiratory distress.

PPC/2014/Death 3

Factors that affect quality of dying and death in terminal cancer patients on inpatient palliative care units: Perspectives of bereaved family caregivers

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J Pain Symptom Manage. 2013;45(4):735–45

CONTEXT: There is an increasing use of palliative care units (PCUs) for the treatment of terminally ill cancer patients. Thus, it is important to evaluate the
care and quality of life of terminally ill cancer patients treated in PCUs so that improvements can be made. Limited research has investigated the quality of dying and death in PCUs. OBJECTIVES: The aim of this study was to identify factors associated with the quality of dying and death for terminally ill cancer patients in PCUs. METHODS: Data were collected from 570 bereaved family caregivers of terminally ill cancer patients. All patients were registered and died in one of the 40 inpatient PCUs designated by the Korean Ministry of Health and Welfare. We assessed the perceived timing of referral to a PCU; the quality of end-of-life care with the Care Evaluation Scale; and the quality of dying and death with the Good Death Inventory. RESULTS: The perception of appropriate timing of referral, use of a community-based PCU, and higher quality of cancer care as assessed by the Care Evaluation Scale were associated with good dying and death in all domains of the Good Death Inventory. CONCLUSION: The good quality of end-of-life care in a PCU improves the quality of dying in terminally ill cancer patients. The data have the potential to guide the development of interventions aimed at achieving a good quality of dying for patients with terminal cancer.

PPC/2014/Death 4

Advance care planning and dying in nursing homes in Flanders, Belgium: A nationwide survey

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J Pain Symptom Manage. 2013;45(2):223–34

CONTEXT: In Belgium, data on actual advance care planning (ACP) in nursing homes (NHs) are scarce. OBJECTIVES: To investigate the prevalence and characteristics of documented advance directives and physicians’ orders for end-of-life care in NHs, and the authorization of a legal representative in relation to the residents’ demographic and clinical characteristics and care received. METHODS: This was a retrospective cross-sectional study, including all NH residents deceased during September and October 2006 in all 594 NHs in Flanders, Belgium. Structured mail questionnaires about the resident’s characteristics, hospital transfers, palliative care delivery, ACPs, and authorization of legal representatives were completed via the NH administrators and nurses involved in the care of the resident. RESULTS: Administrators of 318 NHs (53.5%) reported 1303 deaths. Nurses provided information about 1240 (95.2%) of these deaths. At the end of life, NH residents often had dementia (65.2%) and were severely dependent (76.1%). Almost half (43.1%) had at least one hospital transfer during the last 3 months of life and two-thirds received palliative care. Half had an ACP, predominantly a physician’s order and less often an advance directive. Having advance directives or physician’s orders was associated with receiving palliative care. Residents with a physician’s order more often died in the NH. Nine percent had an authorized legal representative. CONCLUSION: Prevalence of ACPs and formal authorization of a legal representative were low among the deceased NH residents in Flanders, Belgium. There was a higher prevalence of physicians’ orders, often established after the resident had lost capacity. Initiatives should be developed to stimulate more advance discussion on care options and making end-of-life decision with the residents while they retain capacity.

PPC/2014/Death 5

Voluntary stopping of eating and drinking at the end of life: A ‘systematic search and review’ giving insight into an option of hastening death in capacitiated adults at the end of life

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BMC Palliat Care. 2014;13(1):1

BACKGROUND: The terminally ill person’s autonomy and control are important in preserving the quality of life in situations of unbearable suffering. Voluntary stopping of eating and drinking (VSED) at the end of life has been discussed over the past 20 years as one possibility of hastening death. This article presents a ‘systematic search and review’ of published literature concerned with VSED as an option of hastening death at the end of life by adults with decision-making capacity. METHODS: Electronic databases PubMed, EBSCOhost CINAHL, and Ovid PsyscINFO were systematically searched. In addition, Google Scholar was searched and reference lists of included articles were checked. Data of the included studies were extracted, evaluated, and summarized in narrative form. RESULTS: Overall, out of 29 eligible articles 16 were included in this review. VSED can be defined as an action by a competent, capacitiated person, who voluntarily and deliberately chooses to stop eating and drinking with the primary intention of hastening death because of the persistence of unacceptable suffering. An estimated number of deaths by VSED was only provided by one study from the Netherlands, which revealed a prevalence of 2.1% of deaths/year (on average 2800 deaths/year). Main reasons for patients hastening death by VSED are: readiness to die, life perceived as being pointless, poor quality of life, a desire to die at home, and the wish to control the circumstances of death. The physiological processes occurring during VSED and the supportive care interventions could not be identified through our search. CONCLUSIONS: The included articles provide
marginal insight into VSED for hastening death. Research is needed in the field of theory building and should be based on qualitative studies from different perspectives (patient, family members, and healthcare workers) about physiological processes during VSED, and about the prevalence and magnitude of VSED. Based on these findings, supportive care interventions for patients and family members and recommendations for healthcare staff should be developed and tested.

PPC/2014/Death 6

Insight into advance care planning for patients on dialysis

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J Pain Symptom Manage. 2013;45(1):104–13

CONTEXT: Advance care planning is not included in regular clinical care for patients on dialysis. Insight into life-sustaining treatment preferences and communication about end-of-life care is necessary to develop interventions to improve advance care planning for patients on dialysis.

OBJECTIVES: This cross-sectional observational study aimed to understand the preferences for life-sustaining treatments and communication about end-of-life care and barriers and facilitators to this communication.

METHODS: The following outcomes were assessed in 80 clinically stable dialysis patients: demographics, clinical characteristics, life-sustaining treatment preferences (cardiopulmonary resuscitation and mechanical ventilation, and Willingness to Accept Life-Sustaining Treatment instrument), preference for site of death, quality of communication (Quality of Communication Questionnaire), and barriers and facilitators to communication about end-of-life care (Barriers and Facilitators Questionnaire).

RESULTS: Patients were able to indicate their preferences for life-sustaining treatments and site of death. Preferences for life-sustaining treatments depend on the specific treatment, the expected outcome of treatment, and likelihood of an adverse outcome. Life-sustaining preferences were discussed with the nephrologist by 30.3% of the patients. Quality of the patient–physician communication about end-of-life care was rated poor. This study identified several barriers and facilitators to end-of-life care communication.

CONCLUSION: Patients should receive information about treatment burden, expected outcome, and the likelihood of an adverse outcome when discussing life-sustaining treatments. Quality of patient–physician communication about end-of-life care needs to improve. Barriers and facilitators to communication about end-of-life care provide direction for future interventions to facilitate advance care planning for patients on dialysis.

PPC/2014/Death 7

Living and dying with heart failure in long-term care: Experiences of residents and their family members

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Int J Palliat Nurs. 2013;19(8):375–82

The purpose of this study was to explore the experiences of long-term care (LTC) residents living and dying with heart failure (HF) and their family members. An exploratory descriptive design was used to collect data from seven LTC residents and seven family members. The data were analysed using thematic content analysis. The main themes that emerged from the data were: limited understanding of the HF diagnosis, living with restrictions and other comorbidities, making decisions about transitioning to end-of-life care, and learning and negotiating the lines of communication. Residents and family members communicated with many healthcare providers about managing the HF symptoms but most often worked through the nurse when problems arose or decisions about care needed to be made. The findings from this study contribute to our understanding of residents’ and family members’ experiences in managing residents’ HF in LTC.

PPC/2014/Death 8

Prognostic factors of survival in patients with advanced cancer admitted to home care

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J Pain Symptom Manage. 2013;45(1):56–62

CONTEXT: Data regarding prognostication of life expectancy in patients with advanced cancer are of paramount importance to patients, families, and clinicians. However, data regarding patients followed at home are lacking. OBJECTIVES: The aim of this study was to evaluate the correlation between various factors recorded at the beginning of home care assistance and survival. METHODS: A sample of consecutive patients admitted to two home care programs was surveyed. A preliminary consensus was achieved as to the possible variables easy to be recorded at home. These included age at the time of home care admission, gender, residence, marital status, primary cancer diagnosis, Karnofsky Performance Status (KPS) score, measures of systolic blood pressure and heart rate, cyanosis, use of oxygen, and body temperature. The Edmonton
Bibliography

Symptom Assessment System was used to record the intensity of each symptom. Patients were divided into two groups: patients with a survival of <10 days (short survival) and patients with a survival of 10 days or more (medium-long survival). RESULTS: Three hundred and seventy-four consecutive patients admitted to home care programs were surveyed, of which 187 were male. The mean + SD age was 72.1 ± 12.7 years. The mean survival was 56.2 ± 65 days. Mean survival was 71.5 ± 67 days (287 patients) and 5.6 ± 2.7 days (87 patients) in the short and medium-long survival groups, respectively. No association between type of tumor and survival was observed (P = 0.162). Univariate logistic regression analysis revealed that male gender (P = 0.020), older age (P = 0.012), lower KPS scores (P < 0.0005), systolic blood pressure <100 mmHg (P = 0.003), heart rate >100 beats per minute (P = 0.0006), delirium (P = 0.004), the use of oxygen (P = 0.002), intensity of fatigue (P = 0.006), drowsiness (P < 0.0005), anorexia (P < 0.0005), dyspnea (P < 0.0005), poor sense of well-being (P < 0.0005), and distress score (P < 0.0005) were associated with a survival of <10 days.

Marital status, residence, cognitive function, fever, pain, depression, and anxiety were not found to be significantly correlated with survival. In a multiple logistic regression model, low systolic blood pressure and high heart rate, gender, delirium, use of oxygen, KPS score, drowsiness, anorexia, and dyspnea were significantly correlated with a shorter survival. CONCLUSION: Low systolic blood pressure and high heart rate, male gender, poor KPS score, anorexia, and dyspnea were correlated with a shorter survival. Moreover, patients with low systolic blood pressure and high heart rate, male gender, poor KPS score, anorexia, and dyspnea were correlated with a shorter survival. METHODS: A qualitative descriptive design was used. Twelve people with moderate-to-severe COPD were interviewed in an outpatient clinic. RESULTS: From the themes elicited, a mental model was created to demonstrate how the participants engaged in a process of mental work to accept their own mortality and subsequently engage in ACP. CONCLUSIONS: Health professionals should not rely solely on illness severity to initiate ACP. Rather, patients from different illness categories should be approached, but with sensitivity to their emotional cues. Participants who were receptive to end-of-life issues enjoyed the DVD. The DVD is a good medium to facilitate discussion, but would be more effective if patients were screened for readiness prior to viewing.

**PPC/2014/Death 10**

**Death talk: Gender differences in talking about one’s own impending death**

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*BMC Palliat Care*. 2014;13(1):8

BACKGROUND: According to common practice based on a generally agreed interpretation of Icelandic law on the rights of patients, healthcare professionals cannot discuss prognosis and treatment with a patient’s family without that patient’s consent. This limitation poses ethical problems, because research has shown that, in the absence of insight and communication regarding a patient’s impending death, patient’s significant others may subsequently experience long-term psychological distress. It is also reportedly important for most dying patients to know that healthcare personnel are comfortable with talking about death and dying. There is only very limited information concerning gender differences regarding death talk in terminal care patients. METHODS: This is a retrospective analysis of detailed prospective ‘field notes’ from chaplain interviews of all patients aged 30–75 years receiving palliative care and/or with DNR (do not resuscitate) written on their charts who requested an interview with a hospital chaplain during a period of 3 years. After all study patients had died, these notes were analyzed to assess the prevalence of patient-initiated discussions regarding their own impending death and whether non-provocative evocation-type interventions had facilitated such communication. RESULTS: During the 3-year study period, 195 interviews (114 men, 81 women) were conducted. According to the field notes, 80% of women and 30% of men initiated death talk within the planned 30-minute interviews. After evoking interventions, 59% (67 of 114) of men and 91% (74 of 81) of women engaged in death talk. Even with these interventions, at the end of the first interview gender differences were still statistically significant (P = 0.001). By the end of the second interview gender difference was less, but still statistically significant (P = 0.001).

**PPC/2014/Death 9**

**Exploring the advance care planning needs of moderately to severely ill people with COPD**

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BACKGROUND: There is no clear consensus on how to approach advance care planning (ACP) with people with chronic obstructive pulmonary disease (COPD). AIM: This study aimed to explore the perceived ACP needs of people with COPD and to investigate the usefulness of a DVD in meeting these needs.
CONCLUSIONS: Gender differences in terminal care communication may be radically reduced by using simple evocation methods that are relatively unpretentious, but require considerable clinical training. Men in terminal care are more reluctant than women to enter into discussion regarding their own impending death in clinical settings. Intervention based on non-provocative evocation methods may increase death talk in both genders, the relative increase being higher for men.

PPC/2014/Death 11

Advance directives in Japanese nursing homes
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J Pain Symptom Manage. 2013;45(1):63–70.e7

CONTEXT: Advance directives are poorly understood in Japanese nursing homes. In April 2006, additional funding for end-of-life care became available as the first support for terminal care at Japanese nursing homes. OBJECTIVES: The objectives of this study were to investigate the adoption of advance directives by Japanese nursing homes, the effect of additional funding for end-of-life care in nursing homes from long-term care insurance on the use of advance directives, and the types of directives used. METHODS: A nationwide questionnaire survey of nursing homes was performed in Japan. The participants were 913 nursing homes. We investigated the prevalence of advance directives, details of the directives, and demographic data of the responders. RESULTS: Advance directives were used in 58.4% of nursing homes. The timing of introduction of the directives and the results of multivariate analysis at the facility level suggested a relation between the availability of additional funding for end-of-life care and the adoption of advance directives. Most nursing homes used instructional directives, especially directives providing an explanation and informed consent for end-of-life care in the nursing home. CONCLUSION: More than half of Japanese nursing homes have introduced advance directives, and additional funding for end-of-life care is related to their introduction. Most nursing homes have adopted instructional directives, especially those providing an explanation and informed consent regarding end-of-life care at the nursing home.

PPC/2014/Death 12

Motivations of physicians and nurses to practice voluntary euthanasia: A systematic review
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BMC Palliat Care. 2014;13(1):20

BACKGROUND: While a number of reviews have explored the attitude of health professionals towards euthanasia, none of them documented their motivations to practice euthanasia. The objective of the present systematic review was to identify physicians’ and nurses’ motives for having the intention to or performing an act of voluntary euthanasia and compare findings from countries where the practice is legalized to those where it is not. METHODS: The following databases were investigated: MEDLINE/PubMed (1950+), PsycINFO (1806+), CINAHL (1982+), EMBASE (1974+), and FRANCIS (1984+). Proquest Dissertations and Theses (1861+) was also investigated for gray literature. Additional studies were included by checking the references of the articles included in the systematic review as well as by looking at our personal collection of articles on euthanasia. RESULTS: This paper reviews a total of 27 empirical quantitative studies out of the 1703 articles identified at the beginning. Five studies were in countries where euthanasia is legal and 22 in countries where it is not. Seventeen studies were targeting physicians, nine targeted nurses, and one both health professionals. Six studies identified the motivations underlying the intention to practice euthanasia, 16 the behavior itself, and 5 both intention and behavior. The category of variables most consistently associated with euthanasia is psychological variables. All categories collapsed, the four variables most frequently associated with euthanasia are past behavior, medical specialty, whether the patient is depressed, and the patient’s life expectancy. CONCLUSIONS: The present review suggests that physicians and nurses are motivated to practice voluntary euthanasia especially when they are familiar with the act of euthanasia, when the patient does not have depressive symptoms and has a short life expectancy, and their motivation varies according to their medical specialty. Additional studies among nurses and in countries where euthanasia is legal are needed.

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Oxidative stress level is not associated with survival in terminally ill cancer patients: A preliminary study
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BMC Palliat Care. 2014;13(1):14

BACKGROUND: While cancer patients have higher oxidative stress (OS) and lower antioxidant activity, evidence for the association of these parameters with survival in patients with terminally ill cancer is lacking. METHODS: We followed 65 terminal cancer patients prospectively. We assessed their performance status, some symptoms, and serum levels of vitamin C and OS level. The Gehan’s generalized Wilcoxon test was used to examine the association between survival times and variables. RESULTS: Subjects’ performance status was very poor and they
had a high level of OS and a low level of vitamin C. No significant association of these two parameters with survival time was noted (P value, 0.637 for high OS and 0.240 for low vitamin C). Poor performance status was independently related to high OS status after adjusting for potential confounders (adjusted odds ratio, 4.45; P value, 0.031). CONCLUSIONS: In this study, OS was not associated with survival of terminally ill cancer patients and its prognostic role requires further study.

CARERS AND FAMILIES

PPC/2014/Carers 1

Understanding the role of the volunteer in specialist palliative care: A systematic review and thematic synthesis of qualitative studies
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BMC Palliat Care. 2014;13(1):3

BACKGROUND: Volunteers make a major contribution to palliative patient care, and qualitative studies have been undertaken to explore their involvement. With the aim of making connections between existing studies to derive enhanced meanings, we undertook a systematic review of these qualitative studies including synthesizing the findings. We sought to uncover how the role of volunteers with direct contact with patients in specialist palliative care is understood by volunteers, patients, their families, and staff. METHODS: We searched for relevant literature that explored the role of the volunteer including electronic citation databases and reference lists of included studies, and also undertook handsearches of selected journals to find studies which met inclusion criteria. We quality appraised included studies, and synthesized study findings using a novel synthesis method, thematic synthesis. RESULTS: We found 12 relevant studies undertaken in both inpatient and home-care settings, with volunteers, volunteer coordinators, patients, and families. Studies explored the role of general volunteers as opposed to those offering any professional skills. Three theme clusters were found: the distinctiveness of the volunteer role, the characteristics of the role, and the volunteer experience of the role. The first answers the question, is there a separate volunteer role? We found that to some extent the role was distinctive. The volunteer may act as a mediator between the patient and the staff. However, we also found some contradictions. Volunteers may take on temporary surrogate family-type relationship roles. They may also take on some of the characteristics of a paid professional. The second cluster helps to describe the essence of the role. Here, we found that the dominant feature was that the role is social in nature. The third helps to explain aspects of the role from the point of view of volunteers themselves. It highlighted that the role is seen by volunteers as flexible, informal, and sometimes peripheral. These characteristics some volunteers find stressful. CONCLUSIONS: This paper demonstrates how qualitative research can be synthesized systematically, extending methodological techniques to help answer difficult research questions. It provides information that may help managers and service planners to support volunteers appropriately.

PPC/2014/Carers 2

Measuring relatives’ perspectives on the quality of palliative care: The Consumer Quality Index Palliative Care
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J Pain Symptom Manage. 2013;45(5):875–84

CONTEXT: A Consumer Quality Index (CQ-index) is a questionnaire assessing the actual care experiences and how important the recipient finds certain care aspects, as well as the priorities for improving quality. A CQ-index Palliative Care (CQ-index PC) for bereaved relatives was developed to measure the quality of palliative care. OBJECTIVES: This article provides insight into the development and psychometric characteristics of this questionnaire, as well as quality improvement priorities. METHODS: The content of the CQ-index PC was based on existing questionnaires, literature, and interviews and focus group discussions with relatives, patients, and caregivers. The questionnaire was tested in 31 care facilities providing palliative care. Close relatives/contact persons of patients who died non-suddenly 6 weeks to 6 months earlier were eligible for inclusion. Psychometric analyses were performed to shorten the questionnaire and to assess its reliability. ‘Need for improvement scores’ also were computed to identify care aspects with the highest priority for quality improvement. RESULTS: Three hundred and ninety-two bereaved relatives were eligible for inclusion. The net response was 52% (n = 204). Psychometric analyses resulted in six scales (Cronbach’s α ranging from 0.71 to 0.90). The quality aspects relatives considered most important were dying peacefully, getting help in good time in acute situations, and personal attention. Aftercare was the aspect with the highest priority for quality improvement. CONCLUSION: The CQ-index PC for relatives can be used to assess the quality of palliative care from the perspective ofbereaved relatives. This instrument gives healthcare professionals insight into care aspects with the highest priority for quality improvement.
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Effect of communication skills training for residents and nurse practitioners on quality of care in patients with serious illness: A randomized trial
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JAMA. 2013;310(21):2271–81

IMPORTANCE: Communication about end-of-life care is a core clinical skill. Simulation-based training improves skill acquisition, but effects on patient-reported outcomes are unknown. OBJECTIVE: To assess the effects of a communication skills intervention for internal medicine and nurse practitioner trainees on patient- and family-reported outcomes. DESIGN, SETTING, AND PARTICIPANTS: Randomized trial conducted with 391 internal medicine and 81 nurse practitioner trainees between 2007 and 2013 at the University of Washington and Medical University of South Carolina. INTERVENTION: Participants were randomized to an 8-session, simulation-based, communication skills intervention (N = 232) or usual education (N = 240). MAIN OUTCOMES AND MEASURES: Primary outcome was patient-reported quality of communication (QOC; mean rating of 17 items rated from 0 to 10, with 0 = poor and 10 = perfect). Secondary outcomes were patient-reported quality of end-of-life care (QEOLC; mean rating of 26 items rated from 0 to 10) and depressive symptoms (assessed using the 8-item Personal Health Questionnaire (PHQ-8); range, 0–24, higher scores worse) and family-reported QOC and QEOLC. Analyses were clustered by trainee. RESULTS: There were 1866 patient ratings (44% response) and 936 family ratings (68% response). The intervention was not associated with significant changes in QOC or QEOLC. Mean values for post-intervention patient QOC and QEOLC were 6.5 (95% confidence interval (CI), 6.2–6.8) and 8.3 (95% CI, 8.1–8.5) respectively, compared with 6.3 (95% CI, 6.2–6.5) and 8.3 (95% CI, 8.1–8.4) for control conditions. After adjustment, comparing intervention with control, there was no significant difference in the QOC score for patients (difference, 0.4 points (95% CI, −0.1 to 0.9); P = 0.15) or families (difference, 0.1 (95% CI, −0.8 to 1.0); P = 0.81). There was no significant difference in QEOLC score for patients (difference, 0.3 points (95% CI, −0.3 to 0.8); P = 0.34) or families (difference, 0.1 (95% CI, −0.7 to 0.8); P = 0.88). The intervention was associated with significantly increased depression scores among patients of post-intervention trainees (mean score, 10.0 (95% CI, 9.1–10.8), compared with 8.8 (95% CI, 8.4–9.2)) for control conditions; adjusted model showed an intervention effect of 2.2 (95% CI, 0.6–3.8; P = 0.006). CONCLUSIONS AND RELEVANCE: Among internal medicine and nurse practitioner trainees, simulation-based communication training compared with usual education did not improve QOC about end-of-life care or QEOLC but was associated with a small increase in patients’ depressive symptoms. These findings raise questions about skills transfer from simulation training to actual patient care and the adequacy of communication skills assessment. TRIAL REGISTRATION: clinicaltrials.gov Identifier: NCT00687349.

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Burden for family carers at the end of life: A mixed-method study of the perspectives of family carers and GPs
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BMC Palliat Care. 2014;13(1):16

BACKGROUND: Since many patients spend most of the time at home at the end of life, this may affect the burden for family carers and constitute a risk factor for the patients’ hospitalization. This study aimed to explore family carers’ burden in the final 3 months of the patient’s life, from the perspective of both carers and general practitioners (GPs), and to assess whether family burden, as defined by the GP, is associated with hospitalization. METHODS: A cross-sectional nationwide survey among GPs and family carers was performed. Participants were 194 GPs and 74 family carers of patients who died non-suddenly. In addition, in-depth interviews were conducted with 18 family carers. For the quantitative analyses, descriptive statistics, weighted kappa, and multivariate logistic regression analysis were performed. For the qualitative part, thematic analysis was conducted. RESULTS: The proportion of family carers experiencing a fairly heavy or severe burden increased significantly from 32% (second and third months before death) to 66% (1 week before death). Most carers (95%) felt an emotional burden and 29% felt a physical burden in the final week. Three-quarters of carers did not perceive their burden as a problem because caring often felt rewarding. No significant association was found between the characteristics of family caregivers or professional care and the degree of family caregiver burden. Also, there was no significant evidence that patients of family carers for whom the GP assessed a fairly heavy or severe burden, were more likely to be hospitalized. CONCLUSIONS: The different overall assessment of family carers’ burden between GPs and family carers and the increasing emotional and physical burden of family carers towards the end constitute relevant information for GPs that will help them understand and anticipate carers’ personal needs.
OBJECTIVES: To assess the importance and desired timing of end-of-life care (EOLC) discussions among women with gynecologic cancer. METHODS: A questionnaire related to EOLC issues was distributed to patients with gynecologic cancer. Answers were analyzed via SPSS using descriptive statistics. Contingency analysis was done to evaluate for differences among disease status and age regarding preferences for timing of discussions. RESULTS: Patients expressed that addressing EOLC is an important part of their treatment. Most patients were familiar with advanced directives (73.0%), do not resuscitate/do not intubate (88.5%), and hospice (97.5%). Designating someone to make decisions was significantly related to disease status (P = 0.03) and age (P = 0.02). CONCLUSIONS: Patients are familiar with basic EOLC with optimal timing for discussions at disease progression or when treatment is no longer available.

Direct observation of prognosis communication in palliative care: A descriptive study

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J Pain Symptom Manage. 2013;45(2):202-12

CONTEXT: Palliative care (PC) consultations result in improved patient understanding of prognosis and better quality of life, yet the content and processes of prognosis communication during PC consultations remain unknown. OBJECTIVES: To describe prognosis communication during PC consultation with seriously ill hospitalized patients. METHODS: We audio recorded 71 sequential inpatient PC consultations (initial visit) with seriously ill patients and their families who were referred for ‘goals of care’ clarification or help with ‘end-of-life decision making’. Conversations were coded using reliable methods and we then linked conversation codes to clinical record and clinician interview data. RESULTS: Ninety-three percent of consultations contained prognosis communication. Participants communicated prognoses regarding quality of life more frequently than survival; focused prognosis estimates on the unique patient more frequently than on a general population; and framed prognosis using pessimistic cues more frequently than optimistic ones. Prognoses were more commonly spoken by PC clinicians than by patients/families. The following two factors demonstrated an association with the rate of prognostic communication and with the pessimistic framing of that information: whether the patient, family, or both participated in the conversation, and shorter expected survival (as estimated by the attending physician). CONCLUSION: Prognoses are routinely communicated in PC consultations with hospitalized patients and their families. The rate and characteristics of prognosis communication differ based on the length of time the patient is expected to live.

Communication and trust in the care provided to a dying parent: A nationwide study of cancer-bereaved youths

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J Clin Oncol. 2013;31(23):2886–94

PURPOSE: To assess children’s trust in the care provided to a dying parent during the final week of life in relation to end-of-life medical information about disease, treatment, and death. METHODS: This nationwide population-based survey included 622 (73%) of 851 youths who, 6-9 years earlier, at age 13–16 years, lost a parent to cancer. We asked about the children’s reception of end-of-life professional information and trust in the care provided. We also asked about depression and several potential risk factors of distrust in the care provided. RESULTS: A majority (82%) reported moderate/very much trust in the care provided. Compared with children who received end-of-life medical information before their loss, the risk of distrust in the care provided was higher in those who received no information (risk ratio (RR), 2.5; 95% confidence interval (CI), 1.5-4.1), in those who only received information afterward (RR, 3.2; 95% CI, 1.7-5.9), and in those who did not know or remember if end-of-life medical information before their loss, the risk of distrust in the care provided was higher in those who received no information (risk ratio (RR), 2.5; 95% confidence interval (CI), 1.5-4.1), in those who only received information afterward (RR, 3.2; 95% CI, 1.7-5.9), and in those who did not know or remember if end-of-life medical information was provided (RR, 1.7; 95% CI, 1.1-2.5). Those reporting distrust in the care provided had an RR of 2.3 (95% CI, 1.5-3.5) for depression. Furthermore, the risk of distrust in the care provided was higher among children reporting poor efforts to cure (RR, 5.1; 95% CI, 3.6-7.3), and/or a poor relationship with the surviving parent (RR, 2.9; 95% CI, 2.0-4.1). CONCLUSION: Our study suggests that children’s trust in the care provided to a dying parent was highest when they received end-of-life medical information before their loss.
CONCLUSION: Patients with advanced cancer and their families found that Dignity Therapy had helped them in many ways; however, patients in the control group sometimes perceived similar benefits from them in many ways; however, patients in the control group.

CONTEXT: Participants in a Phase II randomized controlled trial of Dignity Therapy felt that the intervention had helped them; however, the processes underlying this are not known. OBJECTIVES: To explore intervention and control participants’ perceptions of the benefits of taking part in an evaluation of Dignity Therapy within the frame of the underlying model of the intervention. METHODS: We interviewed 29 patients at 1-week follow-up and 20 at 4-week follow-up. We also interviewed nine family members of patients in the intervention group. We used the Framework approach to qualitative analysis. This comprised five stages: familiarization, identifying a thematic framework, indexing, charting, and mapping and interpretation. The analysis was both deductive (a priori themes from the model informing the content and therapeutic tone of the intervention) and inductive (from participants’ views). RESULTS: There was support for five of the seven themes from the model underlying Dignity Therapy: ‘generativity’, ‘continuity of self’, ‘maintenance of pride’, ‘hopefulness’, and ‘care tenor’. With the exception of generativity, all were evident in both groups. Prevalent emergent themes for the intervention group were ‘reminiscence’ and ‘pseudo life review’. ‘Making a contribution’ was prevalent in the control group. CONCLUSION: Patients with advanced cancer and their families found that Dignity Therapy had helped them in many ways; however, patients in the control group sometimes perceived similar benefits from taking part in the study, highlighting elements of Dignity Therapy that are common to dignity conserving care.

Anticipatory grief among close relatives of persons with dementia in comparison with close relatives of patients with cancer

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Close relatives of persons with dementia self-reported reactions on the Anticipatory Grief Scale, were observed by nurses (Study I), and compared with relatives of cancer patients in a study using the same methodology (Study II). Study I showed an overall stressful situation including feelings of missing and longing, inability to accept the terminal fact, preoccupation with the ill, tearfulness, sleeping problems, anger, loneliness, and a need to talk. The ability to cope was, however, reported high. Self-assessments and nurses’ observations did not always converge, e.g. for the acceptance of the illness. The reactions of the relatives in the dementia and the cancer groups showed more similarities than dissimilarities. However, the higher number of responding spouses in the cancer group may have influenced the outcome.
A social capital framework for palliative care: Supporting health and well-being for people with life-limiting illness and their carers through social relations and networks

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J Pain Symptom Manage. 2013;45(1):92–103

CONTEXT: Social relations and networks are vital for sustaining and enhancing end-of-life care. The social capital concept supports a framework to understand the association between social relations and well-being; yet, to date, there has been very limited investigation of social capital in the palliative care literature. A framework for understanding social contexts in end-of-life care is necessary. OBJECTIVES: To summarize the literature on social capital, well-being, and quality of life for key outcomes to inform a model of social capital in palliative care. METHODS: The electronic databases MEDLINE (1997 to March 2011), Embase (1997 to March 2011), CINAHL (1997 to March 2011), PsycINFO (1997 to March 2011) were searched using key/McSH search terms of ‘social capital’, ‘palliative care’, and ‘well-being’ and/or ‘quality of life’. The literature was reviewed to identify key concepts to develop and inform a palliative care social capital framework. RESULTS: A total of 93 articles were included in the literature review, with only two articles identifying discourse on social capital and palliative care. Four key areas integrating the social capital outcomes informed a framework for palliative care. CONCLUSION: The social capital concept provides a structure for understanding how the organization and meaning of social contexts can potentially enhance or hinder end-of-life care. Research that identifies specificity in application of social capital concepts is fundamental to issues of access to services, sustaining levels of care, quality of life, and well-being. The importance of ‘bridged’ social capital relations and networks for improved resource acquisition and information flow was identified in the literature and outlined within the palliative care social capital framework. Differential access to social capital by disadvantaged groups provides further impetus to engage a model of social capital for palliative care.

The perspectives of bereaved family members on their experiences of support in palliative care

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Int J Palliat Nurs. 2013;19(6):282–8

AIM: To explore family members’ supportive interactions in palliative care and the emotional experiences that they associate with these interactions. METHODS: Qualitative individual interviews were performed with bereaved family members recruited from an urban palliative care service in Sweden. The interviews were analysed using inductive qualitative content analysis. RESULTS: Five categories of supportive interactions with staff members were linked with emotional consequences: informational support, supportive encounters, professional focus of staff, a supportive environment, and bereavement support. Having a dialogue with family members nurtured certainty and security, supportive encounters gave a warm and comforting feeling, and bereavement support contributed to feelings of strength. Environmental factors contributed to dignity. CONCLUSION: Supportive interactions with staff and within a home-like environment help to build resilience if tailored to the family member’s own needs.

Emotional numbness modifies the effect of end-of-life discussions on end-of-life care

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J Pain Symptom Manage. 2013;45(5):841–7

CONTEXT: Overall, end-of-life (EOL) discussions are unrelated to psychological distress and associated with lower rates of aggressive care near death. Nevertheless, patients who report that they feel emotionally numb about their illness might encounter difficulties cognitively processing an EOL discussion. OBJECTIVES: We hypothesized that emotional numbness would modify the effect of EOL discussions on the receipt of less aggressive EOL care. METHODS: Data were derived from structured interviews with 290 participants in the federally funded Coping with Cancer Study, a multisite, prospective cohort study of patients with advanced cancer followed up till their death. Patients’ reports of EOL discussions with their physician and emotional numbness were assessed at a median of 4.6 months before their death. Information about aggressive EOL care (i.e. ventilation, resuscitation in the last week of life, death in the intensive care unit) was obtained from postmortem caregiver interviews and medical charts. Main and interactive effects of EOL discussions and emotional numbness on aggressive EOL care, adjusting for potential confounds, were evaluated using multiple logistic regression. RESULTS: The likelihood of aggressive EOL care associated with having EOL discussions increased by a factor of nine (adjusted odds ratio = 9.02, 95% confidence interval 1.37, 59.6, P = 0.022) for every unit increase in a patient’s emotional numbness score. CONCLUSION: Emotional numbness diminishes a patient’s capacity to benefit from EOL discussions. The EOL decision making may be more effective if clinical communications with emotionally numb patients are avoided.
Both maintaining hope and preparing for death: Effects of physicians’ and nurses’ behaviors from bereaved family members’ perspectives
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J Pain Symptom Manage. 2013;45(5):848–58

CONTEXT: Both maintaining hope and preparing for death are important for families of terminally ill cancer patients. OBJECTIVES: The primary aim of this study was to clarify the level of the family’s achievement of maintaining hope and preparing for death and the professional’s behavior related to their evaluations. METHODS: A cross-sectional, anonymous, nationwide survey was conducted involving 663 bereaved families of cancer patients who had been admitted to 100 palliative care units throughout Japan. RESULTS: A total of 454 family members returned the questionnaire (effective response rate, 68%). Overall, 73% of families reported that they could both maintain hope and prepare for the patient’s death. The independent determinants of the family’s agreement in reference to the professional’s behavior are pacing the explanation with the family’s preparation; coordinating patient and family discussions about priorities while the patient was in better condition; willingness to discuss alternative medicine; maximizing efforts to maintain the patient’s physical strength (e.g. meals, rehabilitation); discussing specific, achievable goals; and not saying ‘I can no longer do anything for the patient’. CONCLUSION: About 20% of family members reported that they could neither ‘maintain hope nor prepare for death’. A recommended care strategy for medical professionals could include (1) discussing achievable goals and preparing for the future and pacing explanation with the family’s preparation, (2) willingness to discuss alternative medicine, (3) maximizing efforts to maintain the patient’s physical strength, and (4) avoid saying they could do nothing further for the patient.

Explicit prognostic information and reassurance about non-abandonment when entering palliative breast cancer care: Findings from a scripted video-vignette study
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J Clin Oncol. 2013;31(26):3242–9

PURPOSE: When discussing the transition to palliative care for patients with breast cancer, oncologists have to find a balance between giving explicit information while not overwhelming patients and being realistic while remaining hopeful. It is unclear whether patients prefer more or less explicit prognostic information, and reassuring patients that they will not be abandoned may provide realistic hope. We assessed the effect of explicit prognostic information and reassurance about non-abandonment at the transition to palliative care. PATIENTS AND METHODS: An experimental 2×2 study was used. Four scripted videos of a bad news conversation were created that differed only in the level of ‘explicitness of prognosis’ and ‘reassurance about non-abandonment’ (high vs. low). Patients with and survivors of breast cancer (n = 51) and healthy women (n = 53) watched the video vignettes. The effects of the different communications on participants’ anxiety, uncertainty, self-efficacy, and satisfaction were assessed by using multilevel analyses that explored the moderating influences of monitoring/blunting scores. RESULTS: The highly explicit/highly reassuring video yielded the most positive outcomes, and the least explicit/less reassuring video, the most negative (P < 0.05 for all outcome measures except anxiety). The main effects found were that explicitness and reassurance decreased participants’ uncertainty (P < 0.001 and P = 0.002, respectively) and anxiety (only after reassurance; P = 0.001) while increasing self-efficacy (P = 0.004 and P < 0.001, respectively) and satisfaction (P < 0.001 and P < 0.001, respectively). High monitors seemed least positive, mainly following explicitness. CONCLUSION: Explicit prognostic information may lead to better outcomes than general information. In addition, reassurance about non-abandonment might provide realistic hope but should be lived up to. More research is needed to translate these findings into clinical care.

Oncology nurse communication barriers to patient-centered care
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Clin J Oncol Nurs. 2013;17(2):152–8

Although quality communication has been identified as a necessary component to cancer care, communication skills training programs have yet to focus on the unique role of nurses. This study explored communication barriers as reported by seven nurse managers to better identify communication skills needed for oncology nurses to practice patient-centered care. Thematic analysis of transcripts was used to identify barriers to patient and family communication and desirable patient-centered nursing communication skills. Overall, the nurse managers reported that nurses experience patient and family communication difficulties as a result of inconsistent messages to patients and family from other healthcare
staff. Physician assumptions about nursing left nurses feeling uncomfortable asking for clarification, creating a barrier to team communication processes. Patient-centered communication and care cannot be actualized for nurses unless team roles are clarified and nurses receive training in how to communicate with physicians, patients, and family. Therefore, the authors of this article created the COMFORT communication training protocol, and key concepts and resources for nurse communication training through COMFORT are detailed in this article.

**PATIENT CARE SERVICES**

PPC/2014/PAT Serv 1

Delivery strategies to optimize resource utilization and performance status for patients with advanced life-limiting illness: Results from the ‘palliative care trial’ (ISRCTN 81117481)

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*J Pain Symptom Manage.* 2013;45(3):488–505

**CONTEXT:** Evidence-based approaches are needed to improve the delivery of specialized palliative care. **OBJECTIVES:** The aim of this trial was to improve on current models of service provision. **METHODS:** This $2 \times 2 \times 2$ factorial cluster randomized controlled trial was conducted at an Australian community-based palliative care service, allowing three simultaneous comparative effectiveness studies. Participating patients were newly referred adults, experiencing pain, and who were expected to live $>48$ hours. Patients enrolled with their general practitioners (GPs) and were randomized three times: (1) individualized interdisciplinary case conference including their GP vs. control, (2) educational outreach visiting for GPs about pain management vs. control, and (3) structured educational visiting for patients/caregivers about pain management vs. control. The control condition was current palliative care. Outcomes included Australia-modified Karnofsky Performance Status (AKPS) and pain from 60 days after randomization and hospitalizations. **RESULTS:** There were 461 participants: mean age 71 years, 50% male, 91% with cancer, median survival 179 days, and median baseline AKPS 60. Only 47% of individuals randomized to the case conferencing intervention received it; based on *a priori*-defined analyses, 32% of participants were included in final analyses. Case conferencing reduced hospitalizations by 26% (least squares mean hospitalizations per patient: case conference 1.26 (SE 0.10) vs. control 1.70 (SE 0.13), $P = 0.0069$) and better maintained performance status (AKPS case conferences 57.3 (SE 1.5) vs. control 51.7 (SE 2.3), $P = 0.0368$). Among patients with declining function (AKPS < 70), case conferencing and patient/caregiver education better maintained performance status (AKPS case conferences 55.0 (SE 2.1) vs. control 46.5 (SE 2.9), $P = 0.0143$; patient/caregiver education 54.7 (SE 2.8) vs. control 46.8 (SE 2.1), $P = 0.0206$). Pain was unchanged. GP education did not change outcomes. **CONCLUSION:** A single case conference added to current specialized community-based palliative care reduced hospitalizations and better maintained performance status. Comparatively, patient/caregiver education was less effective; GP education was not effective.

PPC/2014/PAT Serv 2

Pattern of hospitalization of patients with cancer in an acute palliative care setting: Qatar’s experience

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Palliative care is an essential part of cancer treatment. Specialized palliative care units are starting to be incorporated into advanced healthcare systems. Qatar, a wealthy country in the Middle East, opened its first acute palliative care unit within a specialty cancer hospital in 2008. The objective of this study is to report and analyze the patterns of admissions and discharges of the patients referred to this unit over a period of 3 years. Our unit received 241 total admissions from July 2008 to June 2011. The age of the patients was 60.5 years, with 41.6% being local Qataris. Gastrointestinal malignancies formed the most common (34.5%). The average length of stay per admission at this unit was 30.5 days. The in-hospital mortality in our unit was 61.7%. The LOS and mortality rates were higher than those reported in the literature. We attributed that to the lack of other models of palliative care in the country and to cultural factors.

PPC/2014/PAT Serv 3

How to analyze palliative care outcome data for patients in sub-Saharan Africa: An international, multicenter, factor analytic examination of the APCA African POS

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**CONTEXT:** The incidence of life-limiting progressive disease in sub-Saharan Africa presents a significant clinical and public health challenge. The ability to easily measure patient outcomes is essential to improving care. **OBJECTIVES:** The present study aims to determine the specific factors (if any) that underpin...
the African Palliative Care Association African Palliative Outcome Scale to assist the analysis of data in routine clinical care and audit. METHODS: Using self-reported data collected from patients with human immunodeficiency virus infection in eastern and southern Africa, an exploratory factor analysis was undertaken with 1337 patients; subsequently, a confirmatory analysis was done on two samples from separate datasets (n = 445). RESULTS: Using exploratory factor analysis initially, both two- and three-factor solutions were examined and found to meet the criteria for simple structure and be readily interpretable. Then using confirmatory factor analysis on two separate samples, the three-factor solution demonstrated better fit, with Goodness-of-Fit Index values >0.95 and Normative Fit Index values close to 0.90. The resulting three factors were (1) physical and psychological well-being, (2) interpersonal well-being, and (3) existential well-being. CONCLUSION: This analysis presents an important new opportunity in the analysis of outcome data for patients with progressive disease. It has advantages over both the total scoring of multidimensional scaling (which masks differences between domains) and of item scoring (which requires repeated analyses). The three factors map well onto the underlying concept and clinical goals of palliative care, and will enable audit of facility care.

_PPC/2014/PAT Serv 4_

**Mapping levels of palliative care development: A global update**

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Our purpose is to categorize palliative care development, country by country, throughout the world, showing changes over time. We adopt a multi-method approach. Development is categorized using a six-part typology: Group 1 (no known hospice-palliative care activity) and Group 2 (capacity-building activity) are the same as developed during a previous study (2006), but Groups 3 and 4 have been subdivided to produce two additional levels of categorization: (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, and (4b) countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision. In 2011, 136 of the world’s 234 countries (58%) had at least one palliative care service – an increase of 21 (+9%) from 2006, with the most significant gains having been made in Africa. Advanced integration of palliative care has been achieved in only 20 countries (8.5%). Total countries in each category are as follows: Group 1, 75 (32%); Group 2, 23 (10%); Group 3a, 74 (31.6%); Group 3b, 17 (7.3%); Group 4a, 25 (10.7%); and Group 4b, 20 (8.5%). Ratio of services to population among Group 4a/4b countries ranges from 1:34 000 (in Austria) to 1:8.5 million (in China); among Group 3a/3b countries, from 1:1000 (in Niue) to 1:90 million (in Pakistan). Although more than half of the world’s countries have a palliative care service, many countries still have no provision, and major increases are needed before palliative care is generally accessible worldwide.

_PPC/2014/PAT Serv 5_

**Middle East experience in palliative care**

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Palliative care (PC) is still a relatively new concept in the Middle East (ME). It was first introduced in Saudi Arabia in 1992 and only recently in countries such as Qatar, Bahrain, and the UAE. Although the majority of Middle-Eastern countries, including Palestine, Iraq, Oman, and Lebanon are in the capacity building phase, others such as Saudi and Jordan already have localized provision. In the absence of any of the ME countries approaching integration with the mainstream service providers, Saudi Arabia and Jordan are currently setting examples of achievement in the field. There are still countries with little or no known PC activity (Yemen and Syria). Political issues, scarcity of resources, and lack of education and awareness seem to be the common factors restricting the progress of this field in most countries. In order to improve the suboptimal PC services in the ME, emphasis should be directed towards providing formal education to professionals and raising awareness of the public. It is also necessary to put all differences aside and develop cross-border collaborations, whether through third-party organizations such as the Middle East Cancer Consortium or otherwise. This review compiles the available literature on the history and progress of the field of PC in most ME countries, while pointing out the major obstacles encountered by the active parties of each country.

**PROFESSIONAL ISSUES**

_PPC/2014/Prof 1_

**Appropriateness and reliability testing of the modified Richmond Agitation-Sedation Scale in Spanish patients with advanced cancer**

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CONTEXT: A tool to quantify agitation severity and sedation level in patients with advanced cancer is needed. OBJECTIVES: To test the appropriateness and reliability of the Richmond Agitation-Sedation Scale (RASS) in Spanish patients with advanced cancer. METHODS: The original RASS was translated into Spanish according to the standard guidelines. Face validity was assessed by members of the palliative care team, and inter-rater reliability was assessed, using a weighted kappa, from observations of patients admitted to the palliative care unit. The association between scores of the RASS, Ramsay Sedation Scale, and Glasgow Coma Scale was evaluated using Spearman’s ρ. RESULTS: Three hundred and twenty-two observations were performed in 156 patients: 116 observations were performed for delirious patients, 76 observations for sedated patients, and 130 observations for patients admitted for other symptom control. The weighted kappa values were practically equal to or greater than 0.90 between nurses and nurses and physicians. The agreement level between observers for each RASS score was roughly 90%. The correlation between the RASS and the Ramsay and Glasgow Scale values was analyzed for 196 observations recorded in 80 patients. The sedation scale of the RASS had a strong correlation with both the Ramsay (Spearman’s ρ, −0.89; P < 0.001) and the Glasgow Coma Scales (Spearman’s ρ, 0.85; P < 0.001). CONCLUSION: These data support the use of the RASS in Spanish patients with advanced cancer.

Overuse or misuse of tests and treatments exposes patients to potential harm. The American Board of Internal Medicine Foundation’s Choosing Wisely campaign is a multiyear effort to encourage physician leadership in reducing harmful or inappropriate resource utilization. Via the campaign, medical societies are asked to identify five tests or procedures commonly used in their field, the routine use of which in specific clinical scenarios should be questioned by both physicians and patients based on the evidence that the test or procedure is ineffective or even harmful. The American Academy of Hospice and Palliative Medicine (AAHPM) was invited, and it agreed to participate in the campaign. The AAHPM Choosing Wisely Task Force, with input from the AAHPM membership, developed the following five recommendations: (1) do not recommend percutaneous feeding tubes in patients with advanced dementia; instead, offer oral-assisted feeding; (2) do not delay palliative care for a patient with serious illness who has physical, psychological, social, or spiritual distress because they are pursuing disease-directed treatment; (3) do not leave an implantable cardioverter-defibrillator activated when it is inconsistent with the patient/family goals of care; (4) do not recommend more than a single fraction of palliative radiation for an uncomplicated painful bone metastasis; and (5) do not use topical lorazepam (Ativan), diphenhydramine (Benadryl), and haloperidol (Haldol) (ABH) gel for nausea. These recommendations and their supporting rationale should be considered by physicians, patients, and their caregivers as they collaborate in choosing those treatments that do the most good and avoid the most harm for those living with serious illness.
research is possible and acceptable to patients and carers.

**Role of the nurse practitioner in providing palliative care in long-term care homes**

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**AIM:** The purpose of this study, which was part of a large national case study of nurse practitioner (NP) integration in long-term care (LTC), was to explore the NP role in providing palliative care in LTC.

**METHODS:** Using a qualitative descriptive design, data were collected from five LTC homes across Canada using 35 focus groups and 25 individual interviews. In total, 143 individuals working in LTC participated, including 9 physicians, 20 licensed nurses, 15 personal support workers, 19 managers, 10 registered nurse team managers or leaders, 31 allied healthcare providers, 4 NPs, 14 residents, and 21 family members. The data were coded and analysed using thematic analysis. **FINDINGS:** NPs provide palliative care for residents and their family members, collaborate with other healthcare providers by providing consultation and education to optimize palliative care practices, work within the organization to build capacity and help others learn about the NP role in palliative care to better integrate it within the team, and improve system outcomes such as accessibility of care and number of hospital visits.

**CONCLUSIONS:** NPs contribute to palliative care in LTC settings through multifaceted collaborative processes that ultimately promote the experience of a positive death for residents, their family members, and formal caregivers.

**Do community specialist palliative care services that provide home nursing increase rates of home death for people with life-limiting illnesses? A systematic review and meta-analysis of comparative studies**

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**CONTEXT:** Systematic reviews and meta-analyses suggest that community specialist palliative care services (SPCSs) can avoid hospitalizations and enable home deaths. But more information is needed regarding the relative efficacies of different models. Family caregivers highlight home nursing as the most important service, but it is also likely the most costly.

**OBJECTIVES:** To establish whether community SPCSs offering home nursing increase rates of home death compared with other models. **METHODS:** We searched MEDLINE, AMED, Embase, CINAHL, the Cochrane Database of Systematic Reviews, and CENTRAL on 2 and 3 March 2011. To be eligible, articles had to be published in English-language peer-reviewed journals and report original research comparing the effect on home deaths of SPCSs providing home nursing vs. any alternative. Study quality was independently rated using Cochrane grades. Maximum likelihood estimation of heterogeneity was used to establish the method for meta-analysis (fixed or random effects). Potential biases were assessed. **RESULTS:** Of 1492 articles screened, 10 articles were found eligible, reporting 9 studies that yielded data for 10 comparisons. Study quality was high in two cases, moderate in three and low in four. Meta-analysis indicated a significant effect for SPCSs with home nursing (odds ratio 4.45, 95% confidence interval (CI) 3.24–6.11; P < 0.001). However, the high-quality studies found no effect (odds ratio 1.40, 95% CI 0.97–2.02; P = 0.071). Bias was minimal. **CONCLUSION:** A meta-analysis found evidence to be inconclusive that community SPCSs that offer home nursing increase home deaths without compromising symptoms or increasing costs. But a compelling trend warrants further confirmatory studies. Future trials should compare the relative efficacy of different models and intensities of SPCSs.

**General nurses’ experiences of end-of-life care in the acute hospital setting: A literature review**

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Approximately 90% of the UK population spends some time in hospital in their final year of life, and more than half of the population die in hospital. This review aims to explore the experiences of general nurses when providing end-of-life care to patients in the acute hospital setting. Nine studies were identified through a literature search, and each was then analysed and evaluated until themes emerged. Six themes were drawn from the literature: lack of education and knowledge, lack of time with patients, barriers arising in the culture of the healthcare setting, communication barriers, symptom management, and nurses’ personal issues. The themes cause concern about the quality of end-of-life care being provided in the acute care setting. The literature appears to be consistent in the view that terminally ill patients are best cared for in specialized care settings, such as palliative care units and hospices. However, increasing demands on health services will result in...
greater numbers of dying patients being admitted to the acute hospital setting. It is therefore paramount that general nurses’ educational needs are met to ensure they develop clinical competence to provide high-quality holistic end-of-life care.

**PPC/2014/Prof 7**

Developing evidence-informed decision making in a hospice: An evaluation of organizational readiness

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INTRODUCTION: Multiprofessional home care and hospice teams should play a part in evidence-informed decision making. AIMS: To assess organizational readiness to adopt evidence-informed decision making in a hospice in England. DESIGN: A mixed-methods approach was used. Clinical staff were surveyed regarding their attitudes to and skills in using evidence, and senior managers completed an organization-based self-assessment tool recording the readiness of the organization to embrace an evidence-informed focus. RESULTS: Eighty-one percent of the staff completed the survey. Staff were committed to the principles of evidence-informed decision making, but overall lacked the necessary knowledge and skills. Information obtained from the management self-assessment highlighted that a priority was to develop an evidence-informed decision-making culture focusing on education, training, and policy development. CONCLUSION: The process used in this evaluation may be applicable to other areas of healthcare when assessing an organization’s readiness to incorporate evidence-informed decision making into policy and procedure.

**PPC/2014/Prof 8**

Cut points on 0–10 numeric rating scales for symptoms included in the Edmonton Symptom Assessment Scale in cancer patients: A systematic review

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CONTEXT: To improve the management of cancer-related symptoms, systematic screening is necessary, often performed by using 0–10 numeric rating scales. Cut points are used to determine if scores represent clinically relevant burden. OBJECTIVES: The aim of this systematic review was to explore the evidence on cut points for the symptoms of the Edmonton Symptom Assessment Scale. METHODS: Relevant literature was searched in PubMed, CINAHL, Embase, and PsycINFO. We defined a cut point as the lower bound of the scores representing moderate or severe burden. RESULTS: Eighteen articles were eligible for this review. Cut points were determined using the interference with daily life, another symptom-related method, or a verbal scale. For pain, cut point 5 and, to a lesser extent, cut point 7 were found as the optimal cut points for moderate pain and severe pain, respectively. For moderate tiredness, the best cut point seemed to be cut point 4. For severe tiredness, both cut points 7 and 8 were suggested frequently. A lack of evidence exists for nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath. Few studies suggested a cut point below 4. CONCLUSION: For many symptoms, there is no clear evidence as to what the optimal cut points are. In daily clinical practice, a symptom score >4 is recommended as a trigger for a more comprehensive symptom assessment. Until there is more evidence on the optimal cut points, we should hold back using a certain cut point in quality indicators and be cautious about strongly recommending a certain cut point in guidelines.

**PPC/2014/Prof 9**

A predictive model to identify hospitalized cancer patients at risk for 30-day mortality based on admission criteria via the electronic medical record

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BACKGROUND: This study sought to develop a predictive model for 30-day mortality in hospitalized cancer patients, by using admission information available through the electronic medical record. METHODS: Observational cohort study of 3062 patients admitted to the oncology service from 1 August 2008, to 31 July 2009. Matched numbers of patients were in the derivation and validation sets (1531 patients). Data were obtained on day 1 of admission and included demographic information, vital signs, and laboratory data. Survival data were obtained from the Social Security Death Index. RESULTS: The 30-day mortality rate of the derivation and validation samples were 9.5 and 9.7%, respectively. Significant predictive variables in the multivariate analysis included age (P < 0.0001), assistance with activities of daily living (ADLs: P = 0.022), admission type (elective/emergency) (P = 0.059), oxygen use (P < 0.0001), and vital signs abnormalities including pulse oximetry (P = 0.0004), temperature (P = 0.017), and heart rate (P = 0.0002). A logistic regression model was developed to predict death within 30 days: score = 18.2897 + 0.6013*(admit
type) + 0.4518*(ADL) + 0.0325*(admit age) – 0.1458*(temperature) + 0.019*(heart rate) – 0.0983*(pulse oximetry) – 0.0123 (systolic blood pressure) + 0.8615*(O2 use). The largest sum of sensitivity (63%) and specificity (78%) was at −2.09 (area under the curve = −0.789). A total of 25.32% (100 of 395) of patients with a score above −2.09 died, whereas 4.31% (49 of 1136) of patients below −2.09 died. Sensitivity and positive predictive value in the derivation and validation samples compared favorably.

CONCLUSIONS: Clinical factors available via the electronic medical record within 24 hours of hospital admission can be used to identify cancer patients at risk for 30-day mortality. These patients would benefit from discussion of preferences for care at the end of life.

**PPC/2014/Prof 10**

**Modeling the longitudinal transitions of performance status in cancer outpatients: Time to discuss palliative care**

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CONTEXT: Understanding the longitudinal transitions of performance status among persons with cancer can assist providers in determining the appropriate time to initiate palliative care support. OBJECTIVES: To model longitudinal transitions of performance status in cancer outpatients, to determine the probabilities of improvement and deterioration in performance status over time, and to evaluate the factors associated with rates of transitions.

METHODS: This population-based, retrospective, cohort study comprised adult outpatients diagnosed with any type of cancer and assessed for performance status throughout their observation period using the Palliative Performance Scale (PPS; scale 0–100; 0 indicates death). At every PPS assessment, patients were assigned to one of four states: stable state (PPS score 70–100), transitional state (PPS score 40–60), end-of-life state (PPS score 10–30), or dead. A Markov multi-state model under the presence of interval censoring was used to examine the rate of state-to-state transitions. RESULTS: There were 11 374 patients representing nearly 71 000 assessments. Patients with lung cancer in the transitional state had a 27.7% chance of being dead at the end of 1 month vs. 17.5% in patients with breast cancer. The average time spent in the transitional state was 6.6 weeks for patients diagnosed with gastrointestinal cancer vs. 8.8 weeks for patients with breast cancer. The rate at which one moves from the transitional state to death was higher for patients with lung cancer than those with breast cancer. CONCLUSION: We estimated the probability and direction of change in performance status in cancer outpatients. Entry into the transitional state may serve as an indicator for referral for palliative care support. Mean end-of-life sojourn times are too short to allow meaningful integration of palliative care.