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Clinical Update: Literature Abstracts

SYMPTOM CONTROL

Occurrence, Severity, and Longitudinal Course of 12 Common Symptoms in 1129 Consecutive Patients during Radiotherapy for Cancer

Hickok, J.T., Morrow, G.R., Roscoe, J.A., Mustian, K., and Okunieff, P.

Journal of Pain and Symptom Management, *20* (2005), 433–442

Little is known about the frequency, severity, and course of symptoms experienced by patients receiving radiotherapy (RT). For this descriptive study, 1129 patients with a variety of cancer diagnoses completed a 12-item Symptom Inventory (SI) at the start of RT; 419 of these patients also completed the SI weekly for an additional 4 weeks (five data points). Eighty-four percent of the 1129 patients were already experiencing symptoms when treatment began. All symptoms significantly increased in frequency over a typical 5-week RT course (all ps $< .001$). Skin problems showed the largest increase. The most common symptoms (fatigue, drowsiness, and sleep problems) were also the most severe. Female patients and patients younger than the median age (59 years) reported significantly more symptoms than males and those 59 years or older. Symptom frequency and severity varied significantly by cancer diagnosis. Improved understanding about the time course and dose response of radiation-induced toxicity will permit more accurate presentation of side-effect risk at the time patient consent is obtained.

Impact of Palliative Care Unit Admission on Symptom Control Evaluated by the Edmonton Symptom Assessment System

Modonesi, C., Scarpi, E., Maltoni, M., Derni, S., Fabbri, L., Martini, F., Sansoni, E., and Amadori, D.

Journal of Pain and Symptom Management, *30* (2005), 367–373

The aim of the present study was to evaluate the impact of palliative care on patients' symptoms, using the Edmonton Symptom Assessment System (ESAS) to measure symptom intensity at the time of admission and variations registered during the first 7 days' hospitalization. Three hundred fourteen patients were admitted to the unit during its first year of activity. Of these, 162 patients (51.6%) completed, 62 (19.7%) partially completed, and 90 (28.7%) did not complete the ESAS. The mean ($\pm SD$) value of the Symptom Distress Score (SDS; sum of the values of the different symptoms) for the 162 evaluable patients on Day 1 was 33.93 ($\pm$16.24). On Day 7 the mean was 28.14 ($\pm$15.11; ANOVA for repeated measurements, $p < .0001$). ESAS values for patients with moderate-severe symptom intensity (average values Day 1–Day 7 and p value, ANOVA for repeated measurements) were as follows: pain (7.12–4.23, $p < .0001$), fatigue (7.46–5.68, $p < .0001$), nausea (7.12–1.96, $p < .0001$), depression (7.26–5.28, $p < .0001$), anxiety (7.13–5.14, $p < .0001$), drowsiness (7.42–6.40, $p = .002$), anorexia (7.33–4.33, $p < .0001$), well-being (6.83–3.85, $p < .0001$), and dyspnea (7.08–3.86, $p < .0001$). These data seem to indicate that the patients who benefit most from inpatient palliative care are those with the most complex symptomatology.

The Impact of Chronic Pain on Depression, Sleep, and the Desire to Withdraw from Dialysis in Hemodialysis Patients

Davison, S.N. and Jhangri, G.S.

Journal of Pain and Symptom Management, *30* (2005) 465–473

Pain is a multidimensional phenomenon with physical, psychological, and social components and is a significant problem for 50% of hemodialysis (HD)

patients. Failure to treat pain adequately may lead to disruption in many aspects of life. This study examines the relationship between moderate to severe chronic pain and depression, insomnia, and the desire to withdraw from dialysis in HD patients. In a cross-sectional study of 205 Canadian HD patients, patients completed a questionnaire that included the Brief Pain Inventory, Beck Depression Inventory, and the Pittsburgh Sleep Quality Index. One hundred and three patients (50.2%) reported chronic pain and 85 (41.4%) moderate to severe pain. There was a higher prevalence of depression in patients with moderate or severe chronic pain compared to patients with mild or no pain (34.1% vs. 18.3%, odds ratio [OR] = 2.31, $p = .01$). Severe irritability, anxiousness, and inability to cope with stress were all more common in patients with pain compared to patients without pain ($p < .001$). There was a higher prevalence of insomnia in patients with moderate or severe chronic pain compared to patients with mild or no pain (74.7% vs. 53.0%, OR = 2.32, $p = .02$). Although consideration of withdrawal from dialysis was significantly associated with moderate or severe pain compared to no or mild pain (46% vs. 16.7%, $p < .001$), death due to withdrawal from dialysis was not. Chronic pain in HD patients is associated with depression and insomnia and may predispose patients to consider withdrawal of dialysis.

Factors Associated with Reductions in Patients' Analgesia at Hospital Discharge

Moore, C., Siu, A., Maroney, C., Fischberg, D., Litke, A., Silberzweig, S., and Morrison, R.S.

Journal of Palliative Medicine, *9* (2006), 41–49

The objective of this study is to describe the patterns of opioid prescribing and the factors associated with reductions in the potency of patients' analgesic medications at the time of hospital discharge using a prospective cohort of 244 patients (171 surgical and 73 nonsurgical) hospitalized in an urban academic medical center who have experienced moderate or severe pain and who are taking opioid analgesics prior to discharge. A step-down (or reduction) in the potency of patients' analgesic medication at the time of discharge was the primary outcome measured. A step-down is defined as the analgesic medication that a patient is prescribed for outpatient analgesia at the time of discharge being less potent than the last pain medication administered to that patient just prior to hospital discharge. Thirty-three percent of all patients had reductions in the potency of their opioid pain medication at the time of discharge (36% for surgical and 26% for nonsurgical patients). For nonsurgical patients, we found a trend toward Hispanic ethnicity being an independent risk factor for having a step-down in analgesic potency at discharge (odds ratio: 3.7, 95% confidence interval: 0.9–14.9). Physicians frequently reduce the potency of hospitalized patients' pain medications at discharge and Hispanic patients may be at increased risk of this occurring. Further research is needed to determine if the reductions in analgesic potency we observed are associated with poor posthospital pain outcomes.

Pain Severity in Diabetic Peripheral Neuropathy Is Associated with Patient Functioning, Symptom Levels of Anxiety and Depression, and Sleep

Gore, M., Brandenburg, N.A., Dukes, E., Hoffman, D.L., Tai, K.S., and Stacey, B.

Journal of Pain and Symptom Management, *30* (2005), 374–385

Our goal was to evaluate pain severity, pain-related interference with function, sleep impairment, symptom levels of anxiety and depression, and quality of life among patients with painful diabetic peripheral neuropathy (DPN). Participants in a burden of illness survey ($n = 255$) completed the modified Brief Pain Inventory-DPN (BPI-DPN), MOS Sleep Scale, Hospital Anxiety and Depression Scale (HADS), Short Form Health Survey-12v2 (SF-12v2), and the EuroQoL (EQ-5D). Patients were 61 ± 12.8 years old (51.4% female), had diabetes for 12 ± 10.3 years and painful DPN for 6.4 ± 6.4 years. Average and worst pain scores (BPI-DPN, 0–10 scales) were 5.0 ± 2.5 and 5.6 ± 2.8. Pain substantially interfered (≥4 on 0–10 scales) with walking ability, normal work, sleep, enjoyment of life, mood, and general activity. Moderate to severe symptom levels of anxiety and depression (HADS-A and HADS-D scores ≥11 on 0–21 scales) occurred in 35% and 28% of patients, respectively. Patients reported greater sleep problems compared with the general U.S. population and significant impairment in both physical and mental functioning (SF-12v2) compared with subjects with diabetes. The mean EQ-5D utility score was 0.5 ± 0.3. Greater pain levels in DPN (mild to moderate to severe) corresponded with higher symptom levels of anxiety and depression, more sleep problems, and lower utility ratings and physical and mental functioning, (all ps $< .01$). Painful DPN is associated with decrements in many aspects of patients' lives: physical and emotional functioning, affective symptoms, and sleep problems. The negative impact is higher in patients with greater pain severity.

Duloxetine versus Routine Care in the Long-Term Management of Diabetic Peripheral Neuropathic Pain

Raskin, J., Smith, T.R., Wong, K., Pritchett, Y.L., D'Souza, D.N., Iyengar, S., and Wernicke, J.F.

Journal of Palliative Medicine, *9* (2006), 29–40

Duloxetine hydrochloride is a dual reuptake inhibitor of both serotonin and norepinephrine. In the present open-label study, the safety of duloxetine at a fixed-dose of 60 mg twice daily (BID) for up to 52 weeks was evaluated and compared to routine care in the therapy of patients diagnosed with diabetic peripheral neuropathic pain (DPNP). Patients who completed a 13-week, double-blind, duloxetine and placebo acute therapy period were rerandomly assigned in a 2:1 ratio to therapy with duloxetine 60 mg BID ($N = 161$) or routine care ($N = 76$) for an additional 52 weeks. Routine care consisted primarily of gabapentin, amitriptyline, and venlafaxine. The study included male or female outpatients 18 years of age or older with a diagnosis of DPNP caused by type 1 or type 2 diabetes. A higher percentage of routine care-treated patients experienced one or more serious adverse events. No statistically significant therapy-group difference was observed in the overall incidence of treatment-emergent adverse events (TEAEs). The TEAE reported by 10% or more of duloxetine 60 mg BID-treated patients was nausea, and by the routine care-treated patients were peripheral edema, pain in the extremity, somnolence, and dizziness. Duloxetine did not appear to adversely affect glycemic control, lipid profiles, nerve function, or the course of DPNP. There were no statistically significant therapy-group differences observed in the 36-item Short-Form Health Survey subscales or in the EuroQol 5-Dimension Questionnaire. In this study, duloxetine was safe and well tolerated compared to routine care in the long-term management of patients with DPNP.

The Association between Anemia and Fatigue in Patients with Advanced Cancer Receiving Palliative Care

Munch, T.N., Zhang, T., Willey, J., Palmer, J.L., and Bruera, E.

Journal of Palliative Medicine, *8* (2005), 144–149

Fatigue has been reported to be associated with anemia in patients receiving cancer treatment. Treatment of anemia such as erythropoietin has been reported to decrease fatigue in these patients. The aim of this paper was to investigate the correlation between anemia and fatigue intensity in patients with advanced cancer receiving palliative care. We reviewed medical charts of 177 consecutive outpatients seen by our palliative care specialists. Information of fatigue intensity and hemoglobin level was collected. Among 147 (83%) evaluable patients, the median hemoglobin level was 11.6 g/dL (range, 7.5–16.1). Eighty-two (56%) patients had a hemoglobin level 12 g/dL or less, whereas 125 (85%) had 10 g/dL or more. The median fatigue score in patients with a hemoglobin level 10 g/dL or more and 10 g/dL or less was 6 (range, 4–8) and 7 (range, 5–8), respectively ($p = .048$). The median fatigue score in patients with a hemoglobin level 12 g/dL or more and 12 g/dL or less was 6 (range, 4–7) and 6 (range, 4–8), respectively ($p > .5$). Spearman's rank correlation coefficient showed a significant association only between the hemoglobin level and the albumin level ($r = .52$, $p < .0001$). Hemoglobin level did not show a significant correlation with fatigue although there was a trend ($p = .09$). In a multivariate regression analysis of the intensity of fatigue and other clinical variables, three variables remained significant in the reverse elimination analysis: depression ($p = .0067$), albumin level ($p = .0079$), and sensation of well-being ($p = .0569$). The overall explained variance for this model was .22. Our findings suggest that anemia is not one of the major contributors to fatigue in patients with cancer receiving palliative care.

Pain and Use of Complementary and Alternative Medicine in a National Sample of Persons Living with HIV

Tsao, J.C., Dobalian, A., Myers, C.D., and Zeltzer, L.K.

Journal of Pain and Symptom Management, *30* (2005), 418–432

The current study investigated the relationship of pain to use of complementary and alternative medicine (CAM) in a U.S. nationally representative sample of 2466 persons with human immunodeficiency virus (HIV), using data from the HIV Cost and Services Utilization Study. Pain was conceptualized as a need characteristic within the context of predisposing, enabling, and need (PEN) characteristics following Andersen's Behavioral Model of Health Services Use. Multivariate analyses were used to examine the association of baseline PEN characteristics with CAM use by follow-up (approximately 6 months later), including use of five specific CAM domains. Change in pain from baseline to follow-up was also examined in relation to CAM use. Baseline pain was a strong predictor of CAM

use, and increased pain over time was associated with use of unlicensed or underground drugs with potential for harm. These results highlight the importance of medical efforts to control pain in persons living with HIV.

Patient Reports of Symptoms and Their Treatment at Three Palliative Care Projects Servicing Individuals with HIV/AIDS

Karus, D., Raveis, V.H., Alexander, C., Hanna, B., Selwyn, P., Marconi, K., and Higginson, I.

Journal of Pain and Symptom Management, *30* (2005), 408–417

Self-reports of 32 symptoms and their treatments were obtained from patients of three palliative care programs that provide services to seriously ill HIV patients (≥95% AIDS) in Alabama (n = 47), Baltimore (n = 91), and New York City (n = 117). On average, patients reported 10.9 (SD = 7.6) to 12.7 (SD = 6.2) symptoms. Pain, lack of energy, and worrying were reported by a majority of patients at all sites, often with a high level of associated distress. For only four symptoms (pain, nausea, difficulty swallowing, and mouth sores) did half or more of patients at all sites experiencing the symptom also report treatment. Less than a third of patients experiencing 12 symptoms (five of six comprising a psychological subscale) reported treatment. Results show that despite the availability of more efficacious treatments, many HIV/AIDS patients continue to experience significant physical and psychological symptomatology. Many of those experiencing symptoms, however, do not perceive their symptoms as being treated.

Patients' and Relatives' Perceptions about Intravenous and Subcutaneous Hydration

Mercadante, S., Ferrera, P., Girelli, D., and Casuccio, A.

Journal of Pain and Symptom Management, *30* (2005), 354–358

Hydration during palliative care is a controversial topic. Most of the arguments are based on anedoctal reports that have not been substantiated with scientific data. Given that the choice is problematic from a clinical perspective, preferences of patients and family should dictate whether intravenous fluids are administered. The aim of this study was to evaluate patient and family perceptions about hydration and two modes of providing hydration. Fifty-four consecutive patients admitted to an acute pain relief and palliative care unit who required hydration completed a questionnaire regarding their perceptions on hydration and modes of hydration. Similarly, the principal family carer was chosen and similar questions were posed. For most items, patients and relatives agreed, considering hydration as a useful medical treatment that is able to provide some nutrition. The intravenous route was considered able to improve the clinical condition and to have a positive psychological meaning, representing an acceptable burden. The subcutaneous route was considered less effective and not less bothersome than the intravenous route. Most patients and relatives agreed with continuing hydration at home, if necessary, preferring the intravenous route. Other than technical considerations, which can be variable according to the clinical setting, the perceived benefits of artificial hydration by the caregivers and patients are central to the ethical, emotional, and cultural considerations involved in their decision making. Most patients and relatives surveyed accepted and were in favor of intravenous hydration.

Efficacy and Safety of Palliative Sedation Therapy: A Multicenter, Prospective, Observational Study Conducted on Specialized Palliative Care Units in Japan

Morita, T., Chinone, Y., Ikenaga, M., Miyoshi, M., Nakaho, T., Nishitateno, K., Sakonji, M., Shima, Y., Suenaga, K., Takigawa, C., Kohara, H., Tani, K., Kawamura, Y., Matsubara, T., Watanabe, A., Yagi, Y., Sasaki, T., Higuchi, A., Kimura, H., Abo, H., Ozawa, T., Kizawa, Y., Uchitomi, Y., and Japan Pain, Palliative Medicine, Rehabilitation, and Psycho-Oncology Study Group

Journal of Pain and Symptom Management, *30* (2005), 320–328

Although palliative sedation therapy is often required in terminally ill cancer patients, its efficacy and safety are not sufficiently understood. The primary aims of this multicenter observational study were to (1) explore the efficacy and safety of palliative sedation therapy, and (2) identify the factors contributing to inadequate symptom relief and complications, using a prospective study design, clearly defined measurement methods, and a consecutive sample from 21 specialized palliative care units in Japan. A sample of 102 consecutive adult cancer patients who received continuous deep sedation were enrolled. Physicians prospectively evaluated the intensity of patient symptoms, communication capacity, respiratory rate, and complications related to sedation. Symptoms were measured on the Agitation Distress Scale, the Memorial Delirium Assess-

ment Scale, and the ad hoc symptom severity scale (0 = *no symptoms*, 1 = *mild and tolerable symptoms*, 2 = in*tolerable symptoms for less than 15 min in the previous 1 h*, and 3 = *intolerable symptoms continuing for more than 15 min in the previous 1 h*). Inadequate symptom relief was defined as the presence of hyperactive delirium (item 9 of the Memorial Delirium Assessment Scale ≥2) or grade 2 or 3 symptom intensity 4 h after sedation. The degree of communication capacity was measured on the Communication Capacity Scale. Palliative sedation therapy succeeded in symptom alleviation in 83% of the cases. Median time elapsed before patients initially had one continuous hour of deep sedation was 60 min, but 49% of the patients awakened once after falling into a deeply sedated state. The percentage of patients who were capable of explicit communication decreased from 40% before sedation to 7.1% 4 h after sedation, and the mean Communication Capacity Score significantly decreased to the level of 15 points ($p < .001$). The respiratory rates did not significantly decrease after sedation (18 ± 9.0 to 16 ± 9.4/min, $p = .62$), but respiratory and/or circulatory suppression (respiratory rate ≤8/min, systolic blood pressure <≤60 mHg, or 50% or more reduction) occurred in 20%, with fatal outcomes in 3.9%. There were no statistically significant differences in patient age, sex, performance status, target symptoms, or classes and initial dose of sedative medications between the patients with adequate and inadequate symptom relief. Respiratory and/or circulatory suppression was significantly more likely to occur in patients receiving sedation for delirium and those with higher levels on the Agitation Distress Scale. Higher dose of midazolam was significantly correlated with younger age, absence of icterus, preexposure to midazolam, and length of sedation. Palliative sedation therapy is effective and safe in the majority of terminally ill cancer patients with refractory symptoms. However, a small number of patients experience fatal complications related to sedation. Comparison studies of different sedation regimens are needed to determine the most effective and safe sedation protocol.

PSYCHOSOCIAL INTERVENTIONS

A Psycho-Educational Intervention for Family Caregivers of Patients Receiving Palliative Care: A Randomized Controlled Trial

Hudson, P.L., Aranda, S., and Hayman-White, K.

Journal of Pain and Symptom Management, *30* (2005), 329–341

This study describes an evaluation of a psychoeducational intervention for family caregivers of patients dying of cancer at home. In a randomized controlled trial, participants ($n = 106$) received standard home-based palliative care services ($n = 52$) or these services plus the new intervention ($n = 54$). Data were collected at three time points: upon commencement of home-based palliative care (Time 1), 5 weeks later (Time 2), and then 8 weeks following patient death (Time 3). No intervention effects were identified with respect to preparedness to care, self-efficacy, competence, and anxiety. However, participants who received the intervention reported a significantly more positive caregiver experience than those who received standard care at both Times 2 and 3. The findings indicate that it is possible to increase caregiver rewards despite being immersed in challenging circumstances that often yield considerable negative psychosocial sequelae. Furthermore, it is feasible for health professionals to discuss emotive topics, such as impending death, with caregivers without adverse effects.

Tactical Reframing to Reduce Death Anxiety in Undergraduate Nursing Students

Mooney, D.C.

The American Journal of Hospice & Palliative Care, *22* (2005), 427–432

The effectiveness of a death education program in reducing death anxiety in Australian undergraduate nursing students was examined. The experimental group ($n = 97$) participated in a death education program conducted over a 13-week period. The comparison group ($n = 122$) included undergraduate students at the same academic level who had enrolled in a health-science program of similar structure, design, and duration as the death education program. No subjects in the comparison group had previously participated in a death education program. All participants were pre- and posttested using the revised Collett-Lester Fear of Death Scale. Posttest analysis indicated that the 13-week death education program was effective in decreasing death anxiety.

Interventions to Facilitate Family Caregiving at the End of Life

McMillan, S.C.

Journal of Palliative Medicine, *8* (2005), S132–S139

Informal family caregivers provide care in a variety of situations, including care for patients receiving active curative treatment for cancer and other life-

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threatening diseases, for Alzheimer's patients over the long trajectory of their disease, and for hospice patients who are near the end of life. Especially at the end of life, these caregivers are essential because they provide needed help with activities of daily living, medications, eating, transportation, and emotional support, as well as communicating with health care professionals about the patients' condition. As health care increasingly moves out of acute care settings and into homes, the role of the caregiver becomes more critical and the burden becomes heavier. There is a paucity of data regarding which caregivers are at greatest risk for distress and which interventions are likely to relieve that distress. Although both educational and supportive interventions have been tested, including both telephone and face-to-face meetings, it still is not clear which approach is best for which groups of caregivers. Much of the research that has been done has been descriptive and evaluative, and only a very limited number of clinical trials have been conducted with caregivers of patients near the end of life. There is limited evidence about whether caregiver interventions at the end of the patient's life have the potential to provide long-term benefits to caregivers. In addition, issues exist in adapting such interventions to work with culturally diverse populations. Sadly, there appears to be a limited number of investigators doing this important work. More research is needed to provide complete evidence on which to base practice and policy decisions.

Interventions to Enhance the Spiritual Aspects of Dying

Chochinov, H.M. and Cann, B.J.

Journal of Palliative Medicine, *8* (2005), S103–S115

In recent years, medical and allied health publications have begun to address various topics on spirituality. Scholars have posited numerous definitions of spirituality and wrestled with the notion of spiritual pain and suffering. Researchers have examined the relationship between spirituality and health and explored, among other topics, patients' perceptions of their spiritual needs, particularly at the end of life. This paper summarizes salient evidence pertaining to spirituality, dying patients, their health care providers, and family or informal caregivers. We examine the challenging issue of how to define spirituality and provide a brief overview of the state of evidence addressing interventions that may enhance or bolster spiritual aspects of dying. There are many pressing questions that need to be addressed within the context of spiritual issues and end-of-life care. Efforts to understand more fully the constructs of spiritual well-being, transcendence, hope, meaning, and dignity, and to correlate them with variables and outcomes such as quality of life, pain control, coping with loss, and acceptance are warranted. Researchers should also frame these issues from both faith-based and secular perspectives, differing professional viewpoints, and in diverse cultural settings. In addition, longitudinal studies will enable patients' changing experiences and needs to be assessed over time. Research addressing spiritual dimensions of personhood offers an opportunity to expand the horizons of contemporary palliative care, thereby decreasing suffering and enhancing the quality of time remaining to those who are nearing death.

Interventions to Enhance Communication among Patients, Providers, and Families

Tulsky, J.A.

Journal of Palliative Medicine, *8* (2005), S95–102.

Whether patient suffering is caused by physical symptoms, unwanted medical intervention, or spiritual crisis, the common pathway to relief is through a provider who is able to elicit these concerns and is equipped to help the patient and family address them. This paper reviews the current state of knowledge in communication at the end of life, organized according to a framework of information gathering, information giving, and relationship building, and then focuses on interventions to enhance communication among patients, providers, and families. Several observations emerge from the existing literature. Patients have highly individualized desires for information and we cannot predict patient preferences. Communication coding methodology has advanced significantly, yet the current systems remain poorly understood and largely inaccessible. Physicians and other health care providers do not discuss sufficiently treatment options and quality of life or respond to emotional cues from patients, and there is plenty of room for improvement. On the positive side, we have also learned that physicians and other health care providers can be taught to communicate better through intensive communication courses, and that communication interventions can improve some patient outcomes. Finally, huge gaps remain in our current knowledge, particularly with regard to understanding the relationship between communication style and outcomes. These findings suggest several recommendations. We should create larger and more diverse data sets, improve upon the analysis of recorded communication data, increase our knowledge about patient preferences for information, establish a stronger

link between specific communication behaviors and outcomes, and identify more efficient ways to teach providers communication skills.

Interventions to Enhance Adaptation to Bereavement

Schut, H. and Stroebe, M.S.

Journal of Palliative Medicine, *8* (2005), S140–S147

This paper reviews quantitative evaluations of the efficacy of intervention programs designed to reduce the pain and suffering associated with bereavement. After identifying the psychological and physical health impacts of bereavement and outlining the prevalence of detrimental outcomes, we conclude that a minority of bereaved persons experience severe and sometimes lasting consequences, whereas the majority manage to overcome their grief across the course of time. We detail criteria for establishing the efficacy of bereavement intervention and examine the impact of intervention according to these stringent criteria. We critically examine previous reviews and summarize their conclusions. Using a narrative review approach, we apply a public health framework to organize intervention programs into primary, secondary, and tertiary prevention strategies. A comprehensive, updated review of empirical studies in these categories leads to the following conclusions: Routine intervention for bereavement has not received support from quantitative evaluations of its effectiveness and is therefore not empirically based. Outreach strategies are not advised, and even provision of intervention for those who believe that they need it and who request it should be carefully evaluated. Intervention soon after bereavement may interfere with "natural" grieving processes. Intervention is more effective for those with more complicated forms of grief. Finally, a research agenda is outlined that includes the use of rigorous design and methodological principles in both intervention programs themselves and in studies evaluating their efficacy, systematic investigation of "risk factors," and comparison of relative effectiveness of different intervention programs (i.e., what works for whom).

MEASURES

Evaluation of Reliability, Validity, and Preference for a Pain Intensity Scale for Use with the Elderly

Miró, J., Huguet, A., Nieto, R., Paredes, S., and Baos, J.

Journal of Pain, *6* (2005), 727–735

The main objective of this research was to determine the initial psychometric properties of the Spanish Version of the Faces Pain Scale-Revised (FPS-R) as a measure of pain intensity for use with the elderly. To assess the scaling properties, validity, and reliability of the FPS-R, a total sample of 177 subjects aged 65 years or older participated in this study. Ranking procedures, placement tasks, and test–retest methods were used. The participants were asked to rate their pain intensity by using the FPS-R and a pain thermometer (PT) and to inform about their affective state. They were also asked to imagine themselves in five hypothetical painful situations (Geriatric Painful Events Inventory) and rate the degree of pain by using the FPS-R and the PT at two different times. Rank ordering tasks for the individual faces showed excellent agreement between the expected ranking and the one provided by the participants (Kendall's $W = 0.75$, $p < .0001$). The pain intensity ratings reported with FPS-R and the PT were very similar, and the relationship between the intensity of pain experienced and participant's negative affective state was statistically significant ($r = .32$, $p < .01$). Test–retest correlations on the Geriatric Painful Events Inventory ranged from .44 to .7. All the participating subjects were asked to choose the pain scale they preferred. Our data suggest that, regardless of their age and/or gender, the subjects preferred the FPS-R to the PT. Overall, these results provide preliminary evidence of its reliability and convergent and criterion-related validity as well as its strong ordinal properties with a sample of elderly subjects. This article presents the evaluation of reliability, validity, and preference for a pain intensity scale for use with the elderly, the Faces Pain Scale-Revised. This scale could help clinicians to assess the intensity of pain in cognitively intact elderly patients and might also be helpful in making decisions about treatment. Likewise, it could be used by researchers who wish to evaluate the effects of available treatments.

Measuring End-of-Life Care Outcomes Prospectively

Steinhauser, K.E.

Journal of Palliative Medicine, *8* (2005), S30–41

This paper discusses the state of the science in prospective measurement in end-of-life research and identifies particular areas for focused attention. Topics include defining the scope of inquiry, evaluating experiences of patients too ill to communicate, the role of proxy and family response, measurement sensitivity to change, the role of theory in guiding measurement efforts, evaluating relation-

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ships between domains of end-of-life experience, and measurement of cultural comprehensiveness. The state of the sciences calls for future research to (1) conduct longitudinal studies to capture transitions in end-of-life trajectories; (2) evaluate the quality of proxy reporting as it varies by rater relationship, domain, and over time; (3) use state-of-the-art psychometric and longitudinal techniques to validate measures and to assess sensitivity to change; (4) develop further and test conceptual models of the experience of dying; (5) study the interrelatedness of multiple dimensions of end-of-life trajectories; (6) compile updated information evaluating available measurement tools; and (7) conduct population-based research with attention to ethnic and age diversity.

Overview of the Domains of Variables Relevant to End-of-Life Care

Ferrell, B.R.

Journal of Palliative Medicine, *8* (2005) S22–S29

Advancing the science of end-of-life care requires a foundation of clear domains and variables to guide research and clinical practice. Palliative care and hospice programs have grown rapidly in recent years in response to an increasing proportion of the population living with chronic, debilitating, and life-threatening illness. Numerous studies and key publications have proposed frameworks that identify key concepts or domains of end-of-life care. A major advance in defining the essential domains of palliative care has been the release in 2004 of national guidelines published by the National Consensus Project for Quality Palliative Care (NCP). This paper reviews and compares several models that have proposed domains of end-of-life care and then applies the domains of the NCP Clinical Practice Guidelines as a framework to identify potential outcome variables for research. Having definitions and concepts shared by scientists in end-of-life care can advance the science and provide an evidence base for practice to improve quality care.

QUALITY OF PALLIATIVE CARE

Psychiatric Disorders and Mental Health Service Use in Patients with Advanced Cancer: A Report from the Coping with Cancer Study

Kadan-Lottick, N.S., Vanderwerker, L.C., Block, S.D., Zhang, B., and Prigerson, H.G.

Cancer, *104* (2005), 2872–2881

Psychological morbidity has been proposed as a source of distress in cancer patients. This study aimed to determine the prevalence of diagnosable psychiatric illnesses and describe the mental health services received and predictors of service utilization in patients with advanced cancer. This was a cross-sectional, multi-institutional study of 251 eligible patients with advanced cancer. Eligibility included distant metastases, primary therapy failure, nonpaid caregiver, age ≥20 years, stamina for the interview, English or Spanish speaking, and adequate cognitive ability. Trained interviewers administered the Structured Clinical Interview for the Diagnostic Statistical Manual IV (DSM-IV) modules for Major Depressive Disorder, Generalized Anxiety Disorder, Panic Disorder, Post-Traumatic Stress Disorder, and a detailed questionnaire regarding mental health service utilization. Overall, 12% met criteria for a major psychiatric condition and 28% had accessed a mental health intervention for a psychiatric illness since the cancer diagnosis. Seventeen percent had discussions with a mental health professional; 90% were willing to receive treatment for emotional problems. Mental health services were not accessed by 55% of patients with major psychiatric disorders. Cancer patients who had discussed psychological concerns with mental health staff (odds ratio [OR] = 19.2; 95% confidence interval [95% CI], 8.90–41.50) and non-Hispanic white patients (OR = 2.7; 95% CI, 1.01–7.43) were more likely to receive mental health services in adjusted analysis. Advanced cancer patients experience major psychiatric disorders at a prevalence similar to the general population, but affected individuals have a low rate of utilizing mental health services. Oncology providers can enhance utilization of mental health services, and potentially improve clinical outcomes, by discussing mental health concerns with their patients.

Late Referral to Hospice and Bereaved Family Member Perception of Quality of End-of-Life Care

Schockett, E.R., Teno, J.M., Miller, S.C., and Stuart, B.

Journal of Pain and Symptom Management, *30* (2005), 400–407

The Family Evaluation of Hospice Services was used to document bereaved family members' perceptions of whether their loved ones were referred too late to hospice and to examine the association of that perception and quality of end-of-life care. A

mortality follow-back survey of bereaved family members from two not-for-profit hospices found that 13.7% of decedents were referred at a time too late for hospice services. Family members of persons referred too late reported lower satisfaction with hospice services, a higher rate of unmet needs for information about what to expect at time of death, lower confidence in participating in patient care at home, more concerns with coordination of care, and lower overall satisfaction. Families reported physicians as an important barrier to earlier hospice referral in nearly one-half of cases. These results indicate a need for improved services for shorter-stay hospice patients/families and for physicians to help facilitate earlier hospice admission.

When Patients Lack Capacity: The Roles that Patients with Terminal Diagnoses Would Choose for Their Physicians and Loved Ones in Making Medical Decisions

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Current approaches to end-of-life decision making are widely considered inadequate. We explored these complexities by examining how patients with terminal diagnoses would choose to involve their physicians and loved ones in making medical decisions, assuming they were able and unable to participate. Cross-sectional interviews of 130 patients recently diagnosed with fatal conditions were conducted. Patients were recruited from two academic medical centers using a modification of the Decision Control Preferences Scale, ranging from independent decision making to decision making that relies on others. Patients were asked how they would balance their own wishes relative to the input of physician and loved ones in making medical decisions and to weigh the input of loved ones relative to physician. Most patients (52%), assuming they had the capacity, would opt to share decision making with their physicians, but 15% would defer to their physicians and 34% would make decisions independently. Similarly, 44% would share decision making with their loved ones, but fewer (6%) would defer to their loved ones. Thirty-nine percent would rely on their physicians' judgments about what would be best for them rather than their own wishes if they became unconscious, compared with 15% who would do so if they were conscious ($p < .001$). Nonetheless, patients were more likely to weigh their loved ones' input more heavily than their physicians' input if they were unconscious (33%) than if they were conscious (7%, $p = .05$). Race, religion, gender, diagnosis, and health status were largely unassociated with patients' decision control preferences. Patients with terminal diagnoses report a wide diversity of decision control preferences, but most would opt to share decision making with their physicians and loved ones. If unable to decide for themselves, they shift toward greater reliance on physician input relative to their own wishes but would weigh loved ones' input more heavily than physician input. Deciding for patients who cannot speak for themselves may be more complex than has previously been reflected in law, policy, or clinical ethics.

Communication between Physicians and Family Caregivers about Care at the End of Life: When Do Discussions Occur and What Is Said?

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Journal of Palliative Medicine, *8* (2005), 1176–1185

Few studies have examined physician–family caregiver communication at the end of life, despite the important role families have in end-of-life care decisions. We examined family caregiver reports of physician communication about incurable illness, life expectancy, and hospice, the timing of these discussions, and subsequent family understanding of these issues. We employed a mixed methods study using a closed-ended survey of 206 family caregivers and open-ended, in-depth interviews with 12 additional family caregivers. Two hundred eighteen primary family caregivers of patients with cancer enrolled with hospice between October 1999 and June 2002. Family caregiver reports provided at the time of hospice enrollment of physician discussions of incurable illness, life expectancy, and hospice. Many family caregivers reported that a physician never told them the patient's illness could not be cured (20.8%), never provided life expectancy (40% of those reportedly told illness was incurable), and never discussed using hospice (32.2%). Caregivers reported the first discussion of the illness being incurable and of hospice as a possibility occurred within 1 month of the patient's death in many cases (23.5% and 41.1%, respectively). In open-ended interviews, however, family caregivers expressed ambivalence about what they wanted to know, and their difficulty comprehending and accepting "bad news" was apparent in both qualitative and quantitative data. Our findings suggest that ineffective communication about end-of-life

issues likely results from both physician's lack of discussion and family caregiver's difficulty hearing the news. Future studies should examine strategies for optimal physician–family caregiver communication about incurable illness, so that families and patients can begin the physical, emotional, and spiritual work that can lead to acceptance of the irreversible condition.

Correspondence between Patients' Preferences and Surrogates' Understandings for Dying and Death

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We examined the agreement between hospice patients' preferences for desired experiences during the last week of life and their surrogates' understandings of those preferences (n = 92 pairs). Analyses included percent agreement, intraclass correlation coefficients, and Bland-Altman plots. Demographic characteristics and communication measures associated with better agreement were identified using t tests and analysis of variance. The median number of items on which patients and family members agreed was 14 of 30 (interquartile range, IQR 10, 16). Preferences with good agreement included both observable and nonobservable experiences. Patients who reported having had conversations about treatment preferences and who reported that their surrogates knew their preferences reported higher agreement. Surrogates display a better understanding of what is important to patients at the end of life if they have had discussions about patient preferences. These discussions may enable surrogates and clinicians to more accurately follow patient preferences.

Men as Caregivers at the End of Life

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Few studies have focused on men as caregivers at the end-of-life. The objective of this secondary data analysis was to examine the experiences of men involved in end-of-life caregiving, focusing on caregiver strain. We used a random sample of Oregon death certificates to telephone survey family caregivers of Oregonians who had died 2 to 5 months earlier in private homes, nursing homes, and other community-based settings. Measurements included single-item indicators and embedded scales to measure caregiver strain and perceived decedent symptom distress. For the 25 husbands, sons, wives, and daughters who reported the highest levels of strain, we also analyzed caregivers' description of the decedent's last few days of life. The sample included 1384 caregiver interviews from a pool of 3048 death certificates. Men constituted 29% of the caregivers, including 15% sons, 9% husbands, and 5% others. In a linear regression model, male gender was a significant predictor of lower caregiver strain ($p <$ .001). The strongest predictor of high end-of-life caregiver strain was the severity of the decedents' symptom distress. The qualitative analysis revealed that men used fewer words than women did to describe their experiences, and, despite subsequently reporting the highest levels of caregiving strain, only 15% of men spontaneously mentioned their own struggles. As caregivers at the end of life, men are less common and less likely to report caregiver strain and decedent symptom distress. Health care professionals should actively ask men about these issues and listen carefully, as their responses may be brief and understated.

Factors Predicting Home Death for Terminally Ill Cancer Patients Receiving Hospital-Based Home Care: The Lyon Comprehensive Cancer Center Experience

Chvetzoff, G., Garnier, M., Perol, D., Devaux, Y., Lancry, L., Chvetzoff, R., Chalencon, J., and Philip, T.

Journal of Pain and Symptom Management, *30* (2005), 528–535

This study aimed to determine factors favoring home death for cancer patients in a context of coordinated home care. A retrospective study was conducted among patients followed up by the home care coordinating unit of the cancer center of Lyon. The main endpoint was place of death. Univariate analysis included general characteristics (age, gender, rural or urban residence, disease), Karnofsky Index (KI), type of care at referral (chemotherapy, palliative care, or other supportive care), and coordinating medical oncologist (MCO) home visits. Significant factors were used in a logistic regression analysis. Of 250 patients, 90 (36%) had home death. Low KI and MCO home visit were correlated with home death (odds ratio, respectively, 2.1 and 3.1). These results indicate that health care support favors home death. A hospital-based home care unit is effective for bridging the gap between community and hospital. MCO home visits offer concrete support to health care professionals, patients, and relatives.

Retrospective Analysis of Antibiotic Use and Survival in Advanced Cancer Patients with Infections

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Infection is common among advanced cancer patients. This study was undertaken to review the pattern of use of antibiotics and to identify potential factors that could affect outcomes after infection. The medical records of all patients with advanced cancer who were enrolled into the palliative care service of a district hospital during the period January 2002 to July 2002 were retrospectively reviewed for infections and the use of antibiotics. Among the eligible 87 patients, 17 did not have any infective episode and 70 had at least one infective episode and accounted for a total of 120 episodes. Sixty-eight episodes were associated with survival for >14 days, and 52 episodes were associated with survival of ≤14 days. The most frequent sites of infection were chest (n = 63, 52.5%), urinary tract (n = 35, 29.2%), and skin/wound (n = 6, 5%). Antibiotics were prescribed for 97.5% (n = 117) episodes. The use of second-line antibiotics was 16.2% (n = 19). By multivariate logistic regression analysis, dyspnea (odds ratio [OR] = 2.6, 95% confidence interval [CI] = 1.1–6.3), antibiotic utilization pattern (empirical therapy [OR = 4.8, 95% CI = 1.7–13.2] vs. therapy according to antibiotic sensitivity), and route of administration (parenteral route [OR = 3.3, 95% CI = 1.3–8.2] vs. oral route) were identified as independent determinants affecting survival after infection. Dyspnea was possibly associated with poor prognosis during the treatment of infections in patients with advanced cancer, and antibiotic therapy according to sensitivity was associated with better prognosis. Further studies are encouraged to verify this. The bioethical principles on the use of antibiotics as a life-sustaining treatment should always be followed.

Parental Narratives of Quality of Life in Children with Leukemia as Associated with the Placement of a Central Venous Catheter

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Thirty mothers of children with leukemia were interviewed about the child's and family's daily routines using a version of the Ecocultural Family Interview. Parental narratives were analyzed qualitatively and quantitatively. Four broad dimensions, encompassing 23 subthemes, were identified: child coping (alpha = .88), child quality of life (alpha = .72), parental coping (alpha = .72), and parental trust in the medical care (alpha = .73). Two objective variables were drawn from the medical charts (time from the diagnosis, time from central venous catheter [CVC] placement). Regression analyses showed that the number of days from the CVC placement (beta = .46) and child coping (beta = .44) significantly predicted children's quality of life, which in turn predicted parental trust in the medical care (beta = .31). The methodological implications of our narrative approach are discussed.

Meeting Palliative Care Needs in Post-Acute Care Settings: "To Help Them Live until They Die"

Hanson, L.C. and Ersek, M.

JAMA, *8* (2006), 681–686

One fourth of U.S. deaths take place in long-term care facilities. As the population ages and hospitals shorten length of stay, these settings will deliver more terminal care. Using an illustrative case of an older patient with metastatic melanoma whose life expectancy was weeks to months, we discuss when potential benefits outweigh the risks of transfer from the hospital to post-acute care settings. To improve continuity of care, we outline communication of treatment goals and orders that anticipate symptom escalation. We discuss criteria physicians can use to identify the settings most able to ensure access to high-quality palliative care. Physicians and patients must consider the advantages and disadvantages of inpatient hospice, nursing homes, and residential care facilities. Post-acute care settings vary in delivery of hospice and other palliative care services, professional nursing services, and support of activities of daily living. Finally, we discuss the evidence that palliative care can be improved in these settings, including innovations in advance care planning, staff training, and systematic changes in clinical care practices. Expanding, replicating, and disseminating these studies will be necessary to improve care for the growing number of persons who die in post-acute care settings.

Role of the Doctor in Relieving Spiritual Distress at the End of Life

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Relief of spiritual distress is a part of good palliative care. This literature review examines journal articles and texts dealing with patient spiritual issues at the end of life to see what constitutes spiritual care, why such issues are felt to be part of health care, and how, when, and by whom they should be explored. It also looks at the anticipated outcomes of addressing spiritual distress. This review also notes recommendations in the literature regarding prerequisite skills and attributes of those providing spiritual care and some tools for spiritual assessment and guidance.

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