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Clinical Update: Literature Abstracts

MEASURES

Measuring the Symptom Experience of Seriously Ill Cancer and Noncancer Hospitalized Patients Near the End of Life with the Memorial Symptom Assessment Scale

Tranmer, J.E., Heyland, D., Dudgeon, D., Groll, D., Squires-Graham, M., and Coulson, K.

Journal of Pain Symptom Management, *25* (2003), 420–429

The aims of this study were twofold: (1) to explore and compare the symptom experience of seriously ill hospitalized cancer and noncancer patients near the end of life using the Memorial Symptom Assessment Scale (MSAS), and (2) to determine if the MSAS is a valid and useful measure of symptom distress for patients with noncancer, terminal conditions. This was a prospective cohort study of hospitalized patients with end-stage congestive heart disease, chronic pulmonary disease, cirrhosis, or metastatic cancer. Eligible patients were interviewed to determine symptom prevalence, severity and distress using the MSAS and levels of fatigue using the Piper Fatigue Scale (PFS). Sixty-six patients with metastatic cancer and 69 patients with end-stage disease were enrolled in the study. There was a significant difference in the prevalence of selected physical symptoms, but not psychological symptoms, between cancer and noncancer patients. There were no significant differences in symptom distress scores, a computed score of frequency, severity, and distress, if the symptom was present. In both groups the principal components factor analysis with varimax rotation yielded one factor comprising psychological symptoms and a second factor comprising three subgroups of physical symptoms. Internal consistency was high for the psychological subscale (Cronbach alpha coefficients of 0.85 for the cancer group and 0.77 for the noncancer group) and for the physical subscale groupings, with coefficients ranging between 0.78 and 0.87. The symptom scores were significantly correlated with measures of fatigue. These findings show that both seriously ill cancer and noncancer patients experience symptom distress, and that the MSAS is a reliable measure of symptom distress in noncancer and cancer patients near the end of life.

Three Instruments to Assess Fatigue in Children with Cancer: The Child, Parent, and Staff Perspectives

Hockenberry, J., Hinds, P., Barrera, P., Bryant, R., Adams-McNeill, J., Hooke, C., Rasco-Baggott, C., Patterson-Kelly, K. Gattuso, J., and Manteuffel, B.

Journal of Pain Symptom Management, *25* (2003), 319–328

The purpose of this study was to develop and test three instruments to measure fatigue in children with cancer from the perspectives of the child, parents, and staff. The study consisted of three phases: instrument development, content validation, and estimations of psychometric properties of the three fatigue instruments. One hundred forty-nine children between the ages of 7 and 12 years presently receiving chemotherapy for cancer, 147 parents, and 124 staff participated in this study. The instruments demonstrated strong initial validity and reliability estimates. This study is the first to provide valid and reliable instruments to measure fatigue in children with cancer.

The Bedside Confusion Scale: Development of a Portable Bedside Test for Confusion and Its Application to the Palliative Medicine Population

Stillman, M., and Rybicki, L.

Journal of Palliative Medicine, *3* (2000), 449–456

Clinical tests for confusion in medically ill patients are frequently burdensome and difficult to use. Available tests lack portability and tend to be shunned in clinical practice by physicians. The authors sought to develop a simple, sensitive bedside

test for confusion. They used a prospective comparison study on an inpatient palliative medicine unit in a large urban hospital. Thirty-one patients were involved in the study, no intervention was made. A two-minute screening test, the Bedside Confusion Scale (BCS), which utilizes an observation of level of consciousness at the time of clinical interaction followed by a timed task of attention, was administered to 31 consecutively admitted patients. The results were compared to a previously validated test, the Confusion Assessment Method (CAM). The BCS and the CAM were scored in standardized fashion and results of the two populations compared. Demographic and clinical characteristics of the patient population, along with the Karnofsky performance scores (KPS) and neurological findings were registered. Using the CAM as the reference standard, the sensitivity of the BCS was 100%. Worsening KPS and more abnormalities on neurological examination were seen across normal (BCS = 0), borderline (BCS = 1), and abnormal (BCS $\geq$ 2) groups ($p >$ 0.01, trend test). In an inpatient palliative medicine population, the BCS correlates with the previously validated CAM and exhibits high sensitivity and essential quality as a useful screening test.

Patient-Related Barriers to Pain Management: The Barriers Questionnaire II (BQ-II)

Gunnarsdottir, S., Donovan, H., Serlin, R., Voge, C., and Ward, S.

Pain, 99 (2002), 385–396

Patients' beliefs can act as barriers to optimal management of cancer pain. The Barriers Questionnaire (BQ) is a tool used to evaluate such barriers. Here, the BQ has been revised to reflect changes in pain management practices, resulting in the Barriers Questionnaire-II (BQII), a 27-item, self-report instrument. This paper presents the results from two studies where the psychometric properties of the BQ-II were evaluated. In the first study, the responses of 27 nurses trained in pain management were compared to responses of a convenience sample of 12 patients with cancer. The results indicated that patients with cancer had higher mean scores on the BQ-II than did nurses trained in pain management. In the second study, a convenience sample of 172 patients with cancer responded to the BQ-II and a set of pain and quality of life (QOL) measures. A factor analysis supported four factors. Factor one, Physiological Effects, consists of 12 items addressing the beliefs that side effects of analgesics are inevitable and unmanageable, concerns about tolerance, and concerns about not being able to monitor changes in one's body when taking strong pain medications. Factor two, Fatalism, consists of three items addressing fatalistic beliefs about cancer pain and its management. Factor three, Communication, consists of six items addressing the concern that reports of pain distract the physician from treating the underlying disease, and the belief that "good" patients do not complain of pain. The fourth factor, Harmful Effects, consists of six items addressing fear of becoming addicted to pain medication and the belief that pain medications harm the immune system. The BQ-II total had an internal consistency of 0.89, and alpha for the subscales ranged from 0.75 to 0.85. The mean (*SD*) score on the total scale was 1.52 (0.73). BQ-11 scores were related to measure of pain intensity and duration, mood, and QOL. Patients who used adequate analgesics for their levels of pain had lower scores on the BQ-II than did patients who used adequate analgesics. The BQ-II is a reliable and valid measure of patient-related barriers to cancer pain management.

The Memorial Anxiety Scale for Prostate Cancer

Roth, A., Rosenfeld, B., Kornblith, A.B., Gibson, C., Scher, H.I., Curley-Smart, T., Holland, J.C., and Breitbart, W.

Cancer, *97* (2003), 2910–2918.

The psychological difficulties facing men with prostate cancer are acknowledged widely, yet identifying men who may benefit from mental health treatment has been a challenging task. The authors developed the Memorial Anxiety Scale for Prostate Cancer (MAX-PC) to facilitate the identification and assessment of men with prostate cancer-related anxiety. This scale consists of three subscales that measure general prostate cancer anxiety, anxiety related to prostate specific antigen (PSA) levels, and fear of recurrence. Ambulatory men with prostate cancer (n = 385 patients) were recruited from clinics throughout the United States. Prior to routine PSA tests, participants completed a *baseline* assessment packet that included the Hospital Anxiety and Depression Scale; the Distress Thermometer; the Functional Assessment of Cancer Therapy Scale, Prostate Module; and measures of role functioning, sleep, and urinary functioning. PSA values from the last three tests were also collected. Follow-up evaluation was completed within two weeks after patients learned of their PSA test result using a subset of these scales. Analysis of the MAX-PC revealed a high degree of internal consistency and test–retest reliability for the total score and for the three subscales, although reliability was

somewhat weaker for the PSA Anxiety Scale. Concurrent validity was demonstrated by correlations between the MAX-PC and measures of anxiety. Overall changes in PSA levels were correlated only modestly with changes in MAX-PC scores (correlation coefficient, 0.13; $P = 0.02$). The MAX-PC appears to be a valid and reliable measure of anxiety in men with prostate cancer receiving ambulatory care.

The Schedule of Attitudes toward Hastened Death: Measuring Desire for Death in Terminally Ill Cancer Patients

Rosenfeld, B., Breitbart, W., Galietta, M., Kaim, M., Funesti-Esch, J., Pessin, H., Nelson, C.J., and Brescia, R.

Cancer, *88* (2000), 2868–2875

The authors examined the reliability and validity of the Schedule of Attitudes toward Hastened Death (SAHD), a self-report measure of desire for death previously validated in a population of individuals with the acquired immunodeficiency syndrome (AIDS), among terminally ill patients with cancer. The authors interviewed 92 terminally ill cancer patients, all with a life expectancy of less than six months, after admission to a palliative care hospital. Patients were administered the SAHD, a clinician-rated measure of desire for death (the Desire for Death Rating Scale [DDRS]), and several measures of physical and psychosocial well-being. The average number of SAHD items endorsed was 4.76 (standard deviation, 4.3); 15 patients (16.3%) endorsed 10 or more items, indicating a high desire for death. Internal consistency was strong (coefficient = 0.88, median item-total correlation = 0.49), as were indices of convergent validity. Total SAHD scores were correlated significantly (correlation coefficient [r] = 0.67) with the DDRS, and somewhat less so with measures of depression ($r = 0.49$) and hopelessness ($r = 0.55$). Lower, but substantial, correlations were observed between the SAHD and measures of spiritual well-being ($r = -0.42$), quality of life ($r = -0.36$), physical symptoms ($r = 0.38$), and symptom distress ($r = 0.38$). No significant correlation was observed between SAHD scores and social support ($r = -0.06$) or pain intensity ($r = 0.16$); however, pain-related functional interference and overall physical functioning were correlated significantly with SAHD scores ($r = 0.31$ and $r = -0.23$, respectively). The SAHD appears to be a reliable and valid measure of desire for death among terminally ill cancer patients. Coupled with previous research in patients with AIDS, these results support the utility of the SAHD for research addressing interest in hastened death in patients with life-threatening medical illness.

SYMPTOM CONTROL

Fatigue and Sleep Disturbance in Patients with Cancer, Patients with Clinical Depression, and Community-Dwelling Adults

Anderson, K. Getto, C., Mendoza, T., Palmer, S., Wang, X., Reyes-Gibby, C., and Cleeland, C.

Journal of Pain Symptom Management, *25* (2003), 307–318

This study compared the severity of fatigue in patients with cancer to the fatigue reported by depressed psychiatric patients and community-dwelling adults. Data were collected for this study during the process of validating a new fatigue assessment tool, the Brief Fatigue Inventory (BFI). The sample included 354 cancer patients, 72 psychiatric patients, and 290 nonpatient volunteers. Study subjects reported severity of fatigue and the degree to which fatigue interfered with various aspects of life. Data were also collected on sleep disturbance and demographic variables that might correlate with fatigue. The psychiatric patients reported significantly higher levels of fatigue and fatigue-related interference than the cancer patients, who reported more severe fatigue and interference than the community subjects. The sleep disturbance scores of the cancer patients and the community subjects were significantly correlated with fatigue severity. Although the majority of the psychiatric patients reported sleep disturbance, their sleep disturbance scores were not significantly associated with fatigue severity.

Estimation of Confusion Prevalence in Hospice Patients

Nowels, D., Bublita, C., Kassner, C., and Kutner, J.

Journal of Palliative Medicine, *5* (2003), 687–695

Confusion is common among ill patients and has broad consequences for their care and well-being. The prevalence of confusion in hospice patients is unknown. The authors describe the prevalence, severity, and manifestations of nurse-identified confusion and estimate the prevalence of delirium in hospice patients. In a cross-sectional descriptive study of 19 hospices in the Population-based Palliative Care Research Network (PoPCRN), adult patients receiving care from participating hospices from February 15 to April 1, 2000, were reviewed. Hospice nurses estimated prevalence, severity, be-

havioral manifestations, and consequences of confusion during the preceding week. Confused and nonconfused patients were compared using standard bivariate and stratification techniques. Logistic regression identified manifestations associated with problematic confusion. The median age of the 299 patients was 78 years, 59% were female, 52% were living at home, and cancer was the most common diagnosis (54%). Fifty percent were confused during the preceding week; 36% of those were severely confused or disabled by confusion. Compared with nonconfused patients, confused patients were less likely to have cancer (64% vs. 43%, $p = 0.01$). Disorientation to time or place, impaired short-term memory, drowsiness, and easy distractibility were common manifestations of confusion. When present, confusion caused a problem for the patient, someone else, or both 79% of the time. Inappropriate mood, cancer diagnosis, agitation, and age were the variables predicting problematic confusion. Only 14% of confused patients met criteria for delirium. The authors concluded that confusion among hospice patients was common, frequently severe, and usually problematic.

Cannabis Use for Chronic Noncancer Pain: Results of a Prospective Survey

Ware, M., Doyle, C., Woods, R., Lynch, M., and Clark, A.

Pain, 102 (2003), 211–216

There has been a surge in interest in medicinal cannabis in Canada. The authors conducted a questionnaire survey to determine the current prevalence of medicinal cannabis use among patients with chronic noncancer pain, to estimate the dose size and frequency of cannabis use, and to describe the main symptoms for which relief was being sought. Over a six-week period in mid-2001, 209 chronic noncancer pain patients were recruited in an anonymous cross-sectional survey. Seventy-two (35%) subjects reported ever having used cannabis. Thirty-two (15%) subjects reported having used cannabis for pain relief (pain users), and 20 (10%) subjects were currently using cannabis for pain relief. Thirty-eight subjects denied using cannabis for pain relief (recreational users). Compared to never users, pain users were significantly younger ($P = 0.001$) and were more likely to be tobacco users ($P = 0.0001$). The largest group of patients using cannabis had pain caused by trauma and/or surgery (51%), and the site of pain was predominantly neck/upper body and myofascial (68% and 65%, respectively). The median duration of pain was similar in both pain users and recreational users (8 vs. 7 years; $P = 0.7$). There was a wide range of amounts and frequency of cannabis use. Of the 32 subjects who used cannabis for pain, 17 (53%) used four puffs or less at each dosing interval, eight (25%) smoked a whole cannabis cigarette (joint) and four (12%) smoked more than one joint. Seven (22%) of these subjects used cannabis more than once daily, five (16%) used it daily, eight (25%) used it weekly and nine (28%) used it rarely. Pain, sleep, and mood were most frequently reported as improving with cannabis use, and "high" and dry mouth were the most commonly reported side effects. The authors conclude that cannabis use is prevalent among the chronic noncancer pain population, for a wide range of symptoms, with considerable variability in the amounts used. Discussions between patients and health care providers concerning cannabis use may facilitate education and follow up, and would allow side affects and potential interactions with other medications to be monitored. Clinical trials of cannabis for chronic noncancer pain are warranted.

Outcome from Integrated Pain Management Treatment for Recovering Substance Abuser

Currie, S., Hodgins, D., Crabtree, A., Jacobi, J., and Armstrong, S.

Journal of Pain, *4* (2003), 91–100

There is little information on the efficacy of pain management for substance abusers with noncancerous chronic pain conditions. The present study describes an outcome evaluation of a pain management group adapted to the needs of patients diagnosed with concurrent chronic pain and substance abuse disorders. A heterogeneous group of 44 patients (66% opioid dependent: 61% musculoskeletal pain) attended a 10-week outpatient group based with a multidisciplinary substance abuse treatment program. Measures of addiction severity, pain, use of self-management techniques, emotional distress, medications use, and functional status were obtained at pretreatment, 3-month, and 12-month follow-ups. Outcome data were analyzed on the group and individual level, the latter using the reliable change index. Intention-to-treat analyses showed significant improvements in pain, emotional distress, medication reduction, and coping style. Half of the patients showed a statistically reliable improvement on at least one outcome measure, and half were opioid free at the 12-month follow-up assessment. These results suggest that persons with concurrent chronic pain and substance use disorders are responsive to an integrated treatment model of pain management and relapse prevention.

College on Problems of Drug Dependence Taskforce on Prescription Opioid Nonmedical Use and Abuse: Position Statement

Zacny, J., Bigelow, G., Compton, P., Foley, K., Iguchi, M., and Sannerud, C.

Drug and Alcohol Dependence, *69* (2003), 215–232

This position paper from the College on Problems of Drug Dependence addresses the issues related to nonmedical use and abuse of prescription opioids. A central theme throughout is the need to strike a balance between risk management strategies to prevent and deter prescription opioid abuse and the need for physicians and patients to have appropriate access to opioid pharmaceuticals for the treatment of pain. The epidemiology of prescription opioid use and abuse is reviewed. Nonmedical use and abuse of prescription opioids are on the rise in the United States, illicit use of several widely prescribed opioids has increased disproportionately more than licit use, and the prevalence of prescription opioid abuse appears to be similar to that of heroin and cocaine abuse. There is a paucity of abuse liability testing of prescription opioids, and methods should be developed to fill critical gaps in our knowledge in this area. The role of regulatory agencies in preventing diversion of prescription opioids and identifying potential sources of diversion are discussed. More research is needed to identify those populations most at risk for abusing prescription opioids, and then to develop appropriately targeted prevention programs. Treatment options are discussed; these depend on whether or not an abuser is in pain. Prescription opioid abuse has harmful ramifications for the legitimate and appropriate use of opioids, including stigmatization, opiophobia, and undertreatment of pain. Recommendations include further epidemiological research, laboratory testing of prescription opioids to determine abuse liability, and clinical trials to determine the efficacy of different approaches to the prevention and treatment of prescription opioid abuse.

Nicotine Patch Therapy Based on Smoking Rate Followed by Bupropion for Prevention of Relapse to Smoking

Hurt, R., Krook, J., Croghan, I., Loprinzi, C., Sloan, J., Novotny, P., Kardinal, C., Knost, J., Tria Tirona, M., Addo, F., Morton, R., Michalak, J., Schaefer, P., Porter, P., and Stella, P.

Journal of Clinical Oncology, *21* (2003), 914–920

The purpose of the study was to determine (1) whether tailored nicotine patch therapy that is based on smoking rate can be carried out in a multisite oncology investigative group practice setting, (2) whether long-term use of bupropion reduces the rate of relapse to smoking in smokers who stop smoking with nicotine patch therapy, and (3) whether bupropion can initiate smoking abstinence among smokers who have failed to stop smoking after nicotine patch therapy. Fourteen North Central Cancer Treatment Group sites recruited generally healthy adult smokers from the general population for nicotine patch therapy and based the patch dosage on smoking rates. At completion of nicotine patch therapy, nonsmoking participants were eligible to be assigned to bupropion or placebo for six months (for relapse prevention) and smoking participants were eligible to be assigned to bupropion or placebo for eight weeks of treatment. Of 578 subjects, 31% were abstinent from smoking at the end of nicotine patch therapy. Of those subjects not smoking at the end of nicotine patch therapy who entered the relapse prevention phase, 28% and 25% were not smoking at six months (the end of the medication phase) for bupropion and placebo, respectively ($P = 0.73$). For those still smoking at the end of nicotine patch therapy, 3.1% and 0.0% stopped smoking with bupropion or placebo, respectively ($P = 0.12$). Tailored nicotine patch therapy for the general population of smokers can be provided in a multisite oncology investigative group setting. Bupropion did not reduce relapse to smoking in smokers who stopped smoking with nicotine patch therapy. Bupropion did not initiate abstinence among smokers who failed to stop smoking with nicotine patch therapy.

Writing Therapy for the Bereaved: Evaluation of an Intervention

O'Connor, M., Nikoletti, S., Kristjanson, L.J., Loh, R., and Willcock, B.

Journal of Palliative Medicine, *6* (2003), 195–204

Bereavement is a risk factor for a wide range of negative outcomes, and therefore interventions are needed to support people adjusting to their new roles and change in identity. Writing has proven to be useful for people adjusting to traumatic experiences. Translating experiences into language and constructing a coherent narrative of the event enables thoughts and feelings to be integrated, leading to a sense of resolution and less negative feelings associated with the experience. Using a writing therapy intervention tailored specifically for bereaved individuals in Western Australia, this study examined the question: "Does a writing therapy intervention reduce grief, lead to greater health

and well-being and lead to greater self-care for bereaved individuals?" The results indicate that for grief and General Health Questionnaire-30 (GHQ-30) scores there was an improvement for all participants, regardless of whether participants received the intervention or not. The results for the effect of writing therapy on self-care demonstrate that there is a greater increase in self-care for the intervention group than for the control group. This trend does not, however, reach statistical significance. Writing therapy offers a useful, cost-effective, and private way of supporting bereaved individuals who may not practice self-care. Future research could be directed toward evaluating the intervention for recently bereaved people or those identified by screening as being particularly vulnerable.

SPIRITUALITY/RELIGION

Importance of Faith on Medical Decisions Regarding Cancer Care

Silvestri, G., Knittig, S., Zoller, J., and Nietert, P.

Journal of Clinical Oncology, *21* (2003), 1379–1382

Decisions regarding cancer treatment choices can be difficult. Several factors may influence the decision to undergo treatment. One poorly understood factor is the influence of a patient's faith on how they make medical decisions. The authors compared the importance of faith on treatment decisions among doctors, patients, and patient caregivers. One hundred patients with advanced lung cancer, their caregivers, and 257 medical oncologists were interviewed. Participants were asked to rank the importance of the following factors that might influence treatment decisions: cancer doctor's recommendation, faith in God, ability of treatment to cure disease, side effects, family doctor's recommendation, spouse's recommendation, and children's recommendation. All three groups ranked the oncologist's recommendation as most important. Patients and caregivers ranked faith in God second, whereas physicians placed it last ($P < 0.0001$). Patients who placed a high priority on faith in God had less formal education ($P < 0.0001$). *Conclusion:* Patients and caregivers agree on the factors that are important in deciding treatment for advanced lung cancer but differ substantially from doctors. All agree that the oncologist's recommendation is most important. This is the first study to demonstrate that, for some, faith is an important factor in medical decision making, more so than even the efficacy of treatment. If faith plays an important role in how some patients decide treatment, and physicians do not account for it, the decision-making process may be unsatisfactory to all involved. Future studies should clarify how faith influences individual decisions regarding treatment.

Effect of Spiritual Well-Being on End-of-Life Despair in Terminally Ill Cancer Patients

McClain, C., Rosenfeld, B., and Breitbart, W.

Lancet, 361 (2003), 1603–1607

The importance of spirituality in coping with a terminal illness is becoming increasingly recognized. The authors aimed to assess the relation between spiritual well-being, depression, and end-of-life despair in terminally ill cancer patients. One hundred sixty patients in a palliative care hospital with a life expectancy of less than three months were interviewed with a series of standardized instruments, including the functional assessment of chronic illness therapy–spiritual well-being scale, the Hamilton depression rating scale, the Beck hopelessness scale, and the schedule of attitudes toward hastened death. Suicidal ideation was based on responses to the Hamilton depression rating scale. Significant correlations were seen between spiritual well-being and desire for hastened death ($r = -0.51$), hopelessness ($r = -0.68$), and suicidal ideation ($r = -0.41$). Results of multiple regression analyses showed that spiritual well-being was the strongest predictor of each outcome variable and provided a unique significant contribution beyond that of depression and relevant covariates. Additionally, depression was highly correlated with desire for hastened death in participants low in spiritual well-being ($r = 0.40, p < 0.0001$) but not in those high in spiritual well-being ($r = 0.20$, $P = 0.06$). Spiritual well-being offers some protection against end-of-life despair in those for whom death is imminent. Our findings have important implications for palliative care practice. Controlled research assessing the effect of spirituality based interventions is needed to establish what methods can help engender a sense of peace and meaning.

Dignity in the Terminally Ill: A Cross-sectional, Cohort Study

Chochinov, H. Hack, T. Hassard, T., Kristjanson, L., McClement, S., and Harlos, M.

Lancet, *360* (2002), 2026–2030

Considerations of dignity are often raised in reference to the care of dying patients. However, little research that addresses this issue has been done. The aim of this study was to identify the extent to which dying patients perceive they are able to main-

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tain a sense of dignity, and to ascertain how demographic and disease-specific variables relate to the issue of dignity in these individuals. The investigators conducted a cross-sectional study of a cohort of terminally ill patients with cancer, who had a life expectancy of less than six months. They enrolled 213 patients from two palliative care units in Winnipeg, Canada, and asked them to rate their sense of dignity. The main outcome measures included: a 7-point sense of dignity item; the symptom distress scale; the McGill pain questionnaire; the index of independence in activities of daily living (IADL); a quality of life scale; a brief battery of self-report measures, including screening for desire for death, anxiety, hopelessness, and will to live; burden to others; and requirement for social support. The results indicated that 16 of 213 patients (7.5%; 95% CI 4–11) indicated that loss of dignity was a great concern. These patients were far more than likely than the rest of the cohort to report psychological distress and symptom distress, heightened dependency needs, and loss of will to live.

Loss of dignity is closely associated with certain types of distress often seen among the terminally ill. Preservation of dignity should be an overall aim of treatment and care in patients who are nearing death.

Existential Concerns of Families of Late-Stage Dementia Patients: Questions of Freedom, Choices, Isolation, Death, and Meaning

Albinsson, L., and Strang, P.

Journal of Palliative Medicine, *6* (2003), 225–235

Previous studies have focused on caregiver burden of families caring for patients with dementia. Very few studies, however, have addressed the existential concerns of families of late-stage dementia patients. The aim of this study was to examine issues of freedom/responsibility, existential isolation, death, and meaning/meaninglessness. Qualitative tape-recorded in-depth interviews with 20 family members were conducted. The transcripts were analyzed with a hermeneutic approach. Taking responsibility (faithfulness, paying back) was generally perceived as rewarding, but in some cases it was more a matter of duty with elements of guilt and obligation. Existential isolation was often the result of interrupted communication with a spouse or parent, having no other relatives left in life, or the role-reversal (i.e., parenting your own parent). Thoughts about the impending death were affected not only by the actual situation but also by previous experiences. Anticipatory grief was common. Some informants described an increased awareness of the finiteness of life, which made them live more intensely in the present. The illness itself was discussed in terms of meaninglessness. Still, many respondents were able to identify meaning in the past (memories), present (daily routines, positive aspects of responsibility) and future (to pass on the patient's life work). The study highlights the importance of not only seeing the physical and psychosocial aspects of caregiving, but also the existential ones that emerge when confronting impending death. Staff need to be more aware of existential issues in order to support families also in existential crisis.

QUALITY OF PALLIATIVE CARE

Surveys to Assess Satisfaction with End-of-Life Care: Does Timing Matter?

Casarett, D., Crowley, R., and Hirschman, K.

Journal of Pain and Symptom Management, *25* (2003), 128–132

The goals of this study were to determine whether postdeath surveys of family members cause more distress if they are administered closer in time to the patient's death, and whether family members are less likely to respond to earlier surveys. Caregivers of hospice patients were randomly assigned to receive a survey at two weeks ($n = 107$) or at six weeks ($n = 100$) after the patient's death. Response rates and self-reported distress experienced in completing the survey were recorded. There were no differences in self-ratings of distress between two- and six-week surveys, and response rates were identical (two-week: 54%; six-week: 54%). Distress and response rate do not appear to be influenced by the timing of data collection, even when surveys are administered very soon after death.

Is There Evidence That Palliative Care Teams Alter End-of-Life Experiences of Patients and Their Caregivers?

Higginson, I., Finlay, I., Goodwin, D., Hood, K., Edwards, A, Cook, A., Douglas, H., and Normand, C.

Journal of Pain and Symptom Management, *25* (2003), 150–168

Palliative care delivery varies widely, and the effectiveness of palliative and hospice care teams (PCHCT) is unproven. To determine the effect of PCHCT, 10 electronic databases (to 2000), 4 relevant journals, associated reference lists, and the grey literature were searched. All PCHCT evaluations were included. Anecdotal and case reports were excluded. Forty-four studies evaluated PCHCT provi-

sion. Teams were home care (22), hospital-based (9), combined home/hospital care (4), inpatient units (3), and integrated teams (6). Studies were mostly Grade II or III quality. Funnel plots indicated slight publication bias. Meta-regression (26 studies) found slight positive effect, of approximately 0.1, of PCHCTs on patient outcomes, independent of team make-up, patient diagnosis, country, or study design. Meta-analysis (19 studies) demonstrated small benefit on patients' pain (odds ratio [OR]: 0.38, 95% confidence interval [CI]: 0.23–0.64), other symptoms (OR: 0.51, CI: 0.30–0.88), and a nonsignificant trend towards benefits for satisfaction and therapeutic interventions. Data regarding home deaths were equivocal. Meta-synthesis (all studies) found wide variations in the type of service delivered by each team; there was no discernible difference in outcomes between city, urban, and rural areas. Evidence of benefit was strongest for home care. Only one study provided full economic cost–benefit evaluation. This is the first study to quantitatively demonstrate benefit from PCHCTs. Such comparisons were limited by the quality of the research.

Dying Patients' Need for Emotional Support and Personalized Care from Physicians: Perspectives of Patients with Terminal Illness, Families, and Health Care Providers

Wenrich, M., Curtis, J., Ambrozy, D., Carline, J., Shannon, S., and Ramsey, P.

Journal of Pain Symptom Management, *25* (2003), 236–246

This study addressed the emotional and personal needs of dying patients and the ways physicians help or hinder these needs. Twenty focus groups were held with 137 individuals, including patients with chronic and terminal illnesses, family members, health care workers, and physicians. Content analyses were performed based on grounded theory. Emotional support and personalization were 2 of the 12 domains identified as important in end-of-life care. Components of emotional support were compassion, responsiveness to emotional needs, maintaining hope and a positive attitude, and providing comfort through touch. Components of personalization were treating the whole person and not just the disease, making the patient feel unique and special, and considering the patient's social situation. Although the levels of emotional support and personalization varied, there was a minimal level, defined by compassion and treating the whole person and not just the disease, that physicians should strive to meet in caring for all dying patients. Participants also identified intermediate and advanced levels of physician behavior that provide emotional and personal support.

Identifying Potential Indicators of the Quality of End-of-Life Cancer Care From Administrative Data

Earle, C., Park, E., Lai, B., Weeks, J., Ayanian, J., and Block, S.

Journal of Clinical Oncology, *21* (2003), 1133–1138

The authors explore potential indicators of the quality of end-of-life services for cancer patients that could be monitored using existing administrative data. Quality indicators were identified by literature review for proposed indicators, focus groups with cancer patients and family members to assess candidate indicators and generate new ideas, and an expert panel ranking the meaningfulness and importance of each potential indicator using a modified Delphi approach.

There were three major concepts of poor quality of end-of-life cancer care that could be examined using currently available administrative data (such as Medicare claims): institution of new anticancer therapies or continuation of ongoing treatments very near death; a high number of emergency room visits, inpatient hospital admissions, or intensive care unit days near the end of life; and a high proportion of patients never enrolled in hospice, only admitted in the last few days of life, or dying in an acute-care setting. Concepts such as access to psychosocial and other multidisciplinary services and pain and symptom control are important and may eventually be feasible, but they cannot currently be applied in most data systems. Indicators based on limiting the use of treatments with low probability of benefit or indicators based on economic efficiency were not acceptable to patients, family members, or physicians.

Several promising claims-based quality indicators were identified that, if found to be valid and reliable within data systems, could be useful in identifying health-care systems in need of improving end-of-life services.

Hospice Use among Medicare Managed Care and Fee-for-Service Patients Dying with Cancer

McCarthy, E., Burns, R., Ngo-Metzger, Q., Davis, R., and Phillips, R.

JAMA, *289* (2003), 2238–2245

For most patients aged 65 years or older with cancer in the United States, hospice services are uni-

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formly covered by Medicare. Hospice care is believed to improve care for patients at the end of life. However, few patients use hospice, and others enroll too late to maximize the benefits of hospice services. Because the type of health insurance may affect use, the authors examined whether patients with Medicare managed care insurance enrolled in hospice earlier and had longer hospice stays than patients with Medicare fee-for-service (FFS) insurance. A retrospective analysis of the last year of life was conducted using the Linked Medicare-Tumor Registry Database in one of nine Surveillance, Epidemiology, and End Results program coverage areas.

A total of 260,090 Medicare beneficiaries aged 66 years or older diagnosed with primary lung (n = 62,117), colorectal (n = 57,260), prostate (n = 59,826), female breast (n = 37,609), bladder (n = 19,598), pancreatic (n = 11,378), gastric (n = 9,599), or liver (n = 2,703) cancer between January 1, 1973, and December 31, 1996, and who died between January 1, 1988, and December 31, 1998 were studied.

The main outcome measures were time from diagnosis to hospice entry and hospice length of stay for patients enrolled in FFS versus managed care plans after adjusting for patient demographics, tumor registry, year of hospice entry, and type and cancer stage. Of the 260,090 patients, most were men (59%), white (85%), and enrolled in FFS (89.7%). Only 54,937 patients (21.1%) received hospice care before death. Hospice use varied by type of primary cancer ranging from 31.8% of patients with pancreatic cancer to 15.6% with bladder cancer. Managed care patients were more likely to use hospice than FFS patients (32.4% vs. 19.8%, $P < 0.001$). Among hospice patients, median (interquartile range) length of stay was longer for managed care versus FFS patients (32 days [11–82] vs. 25 days [9–66], $P < 0.001$). After adjustment, managed care patients had higher rates of hospice enrollment (adjusted hazard ratio [HR], 1.38; 95% CI, 1.35–1.42) and had a longer length of stay (adjusted HR, 0.91; 95% CI, 0.88–0.94) versus FFS patients. Managed care patients were less likely to enroll in hospice within seven days of their deaths (18.6% vs. 22.6%, $P < 0.001$) and somewhat more likely to enroll in hospice more than 180 days before death (7.8% vs. 6.1%, $P < 0.001$); the results for each of the eight cancer diagnoses were similar. Hospice enrollment and length of stay among managed care versus FFS patients differed significantly by region. Medicare beneficiaries enrolled in managed care had consistently higher rates of hospice use and significantly longer hospice stays than those enrolled in FFS. Although these differences may reflect patient and family preferences, these findings raise the possibility that some managed care plans are more successful at facilitating or encouraging hospice use for patients dying with cancer.

CYTOKINES

Are the Symptoms of Cancer and Cancer Treatment Due to a Shared Biologic Mechanism? A Cytokine-Immunologic Model of Cancer Symptoms

Cleeland, C.S., Bennett, G.J., Dantzer, R., Dougherty, P.M., Dunn, A.J., Meyers, C.A., Miller, A.H., Payne, R., Reuben, J.M., Wang, X.S., and Lee, B-N.

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Cancers and cancer treatments produce multiple symptoms that result in a symptom burden for patients. These symptoms include pain, wasting, fatigue, cognitive impairment, anxiety, and depression, many of which coexist. There is growing recognition that at least some of these symptoms may share a common biologic mechanism. In November 2001, basic and clinical scientists met to consider evidence for a cytokine-immunologic model of symptom expression as well as directions for future research. The characteristics of cytokine-induced sickness behavior in animal models have much in common with those of symptomatic cancer patients. Sickness behavior refers to a set of physiologic and behavioral responses observed in animals after the administration of infectious or inflammatory agents or certain proinflammatory cytokines. In some cases, these responses can be prevented by cytokine antagonists. A combination of animal and human research suggests that several cancer-related symptoms may involve the actions of proinflammatory cytokines. Based on the similarities between cancer symptoms and sickness behavior, the authors discussed approaches to further test the implications of the relationship between inflammatory cytokines and symptoms for both symptom treatment and symptom prevention.

Elevation of Cytokine Levels in Cachectic Patients with Prostate Carcinoma

Pfitzenmaier, J., Vesella, R., Higano, C., Noteboom, J., Wallace, D., Jr., and Corey, E.

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Approximately 60–70% of patients with advanced prostate carcinoma (CaP) suffer from cachexia, one of the most devastating conditions associated with advanced malignant disease. The pathophysiology

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of cachexia is multifactorial, and several cytokines, such as tumor necrosis factor α (TNFα) and interleukin (IL)-1, IL-6, and IL-8, may be involved. The objective of the current study was to determine whether cachexia associated with advanced CaP is accompanied by increased serum levels of TNFα, IL-1β, IL-6, and IL-8. Levels of TNFα, IL-1β, IL-6, IL-8, and prostate specific antigen (PSA) were examined in serum samples from normal donors (n = 10 donors), from patients with organ-confined CaP (n = 19 patients), from patients with advanced CaP without cachexia (n = 17 patients), and from patients with cachectic CaP (n = 26 patients). DPC Immulite and Abbott IMx Total-PSA assays were used to determine cytokine and PSA levels, respectively. Levels of TNF, IL-6, and IL-8 were elevated significantly in the group of patients with advanced, cachectic CaP compared with patients who were without cachexia.

In the cachectic patients, levels of TNF were correlated positively with IL-8, and there was no correlation between PSA levels and any of the cytokine levels. IL-1β levels were below the limit of detection in all samples. The current results show that levels of TNF, IL-6, and IL-8 were increased in CaP patients with cachexia. Increased levels of these cytokines were not correlated with PSA levels, suggesting that they are regulated by a mechanism that is independent of PSA synthesis. Additional fundamental research is needed to determine the mechanisms involved and to identify potential therapeutic targets in patients with cachexia.

Cytokines in Depression and Heart Failure

Pasic, J., Levy, W., and Sulllivan, M.

Psychosomatic Medicine, *65* (2003), 181–193

There is a convincing body of evidence linking depression, cardiovascular disease, and mortality. There is also growing evidence that depression is a risk factor for congestive heart failure (CHF) and that CHF patients with major depression have higher rates of mortality and repeat hospitalizations. Currently there are no proposed neurobiological or neuroimmune mechanisms for the comorbidity of heart failure and depression. This review focuses on the recent literature concerning the role of cytokines in CHF and depression as separate conditions. This review also attempts to identify the overlapping immunological mechanisms that have a potential for future research in the pathophysiology of comorbid depression and CHF. Results of current studies suggest that cytokines exert deleterious effects on the heart and that soluble tumor necrosis factor (TNF) receptor 2 leads to reversal of the cardiotoxic effects of TNF, although the clinical significance of this is unclear. Major depression has been associated with alteration of various aspects of the innate immune system, including cellular components (such as microphages, neutrophils, and natural killer cells) and soluble mediators (such as acute-phase reaction proteins and cytokines). It is inconclusive whether antidepressants have immunoregulatory effects.