

Clinical Update: Literature Abstracts

MEASURES

Hospice Attitudes among Assisted Living and Nursing Home Administrators, and the Long-Term Care Hospice Attitudes Scale

Dobbs, D.J., Hanson, L., Zimmerman, S., Williams, C.S., and Munn, J.

Journal of Palliative Medicine, 9 (2006), 1388–1400.

Our objectives were to examine the attitudes of residential care/assisted living (RC/AL) and nursing home (NH) administrators toward hospice and to assess facility and administrator characteristics related to those attitudes. Two exploratory factor analyses of the Hospice Attitudes Questionnaire using principal factors with a promax (oblique) rotation were conducted. One was in a sample of 390 RC/AL and NH administrators from four states (Florida, Maryland, North Carolina, and New Jersey) and the other included NHs from this and a second sample ($n = 244$). Association between facility and administrator characteristics and administrator attitudes toward hospice were examined among the 146 RC/AL administrators. Exploratory factor analysis in the full sample resulted in the 12-item Long-Term Care Hospice Attitudes Scale (LTC-HAS) with four component subscales: (1) emotional and spiritual support (three items, $\alpha = .83$), (2) quality of care (four items, $\alpha = .78$), (3) rapidity of death (three items, $\alpha = .66$), and (4) end-of-life care coordination (two items, $\alpha = .73$). The overall alpha for the 12-item scale was .81. When exploratory factor analysis was conducted on the NH data only, a three-item subscale related to financing and billing ($\alpha = .66$) also emerged. Four facility and three administrator characteristics that were significantly related to hospice attitudes included state, facility type, facility age, affiliation with another level of care, and age, race, and nurse training. Findings from this paper provide insight about RC/AL facility and NH administrators' attitudes toward Hospice using scale data, an area with limited research. They indicate positive attitudes toward Hospice care coordination and that Hospice should supplement, as opposed to replace,

the care provided by facilities. Findings also suggest areas where targeted outreach and further study may be recommended.

PSYCHOSOCIAL INTERVENTIONS

The Diagnosis of Major Depression in Patients with Cancer: A Comparative Approach

Guo, Y., Musselman, D.L., Manatunga, A.K., Gilles, N., Lawson, K.C., Porter, M.R., McDaniel, J.S., and Nemeroff, C.B.

Psychosomatics, 47 (2006), 376–384.

Depressive symptoms not only impair quality of life in cancer patients but constitute an independent risk factor for increased mortality. In order to accurately and efficiently identify depression in cancer patients, the authors developed a biostatistical strategy to identify items of the 21-item, observer-rated Hamilton Rating Scale for Depression (Ham-D) that would optimize the diagnosis of depression among cancer patients. Exhibiting a relatively high sensitivity and specificity, our most optimal diagnostic tool contained six Ham-D items (late insomnia, agitation, psychic anxiety, diurnal mood variation, depressed mood, and genital symptoms). This study may serve as a prototype to generate valid instruments accurate for the diagnosis of major depression in other populations of cancer patients.

Aripiprazole in the Treatment of Delirium

Straker, D.A., Shapiro, P.A., and Muskin, P.R.

Psychosomatics, 47 (2006), 385–391.

Antipsychotic drugs are the primary treatment for symptoms of delirium, but their side effects can be problematic. Treatment of delirium with aripiprazole has yet to be evaluated. The authors report on 14 patients with delirium treated with aripiprazole. Twelve patients had a $> \text{ or } = 50\%$ reduction in Delirium Rating Scale, Revised-98 scores, and 13 showed improvement on Clinical Global Impression scale

scores. There was a low rate of adverse side effects. Aripiprazole may be an appropriate first-line agent for the treatment of delirium because of its minimal effect on QTc interval, weight, lipids, and glucose levels. Controlled comparison studies should be performed to confirm this impression.

Differences in Characteristics and Outcome of Delirium as Based on Referral Patterns

Mittal, D., Majithia, D., Kennedy, R., and Rhudy, J. *Psychosomatics*, 47 (2006), 367–375.

The authors studied factors associated with referral of delirium patients to psychiatry consultation and its outcome implications. Characteristics and treatment outcomes of delirium patients referred to psychiatry were compared with those not referred. Referred patients were younger, had a more hyperactive subtype, greater substance abuse, less comorbid dementia, were more likely to be recognized as having delirium, and be prescribed medications. Improvement in referred patients was indicated by lower readmission rate postdischarge. No differences were noted in length of stay, discharge status, or mortality within 1 year of the index episode. Psychiatric interventions were moderately helpful. Patients' characteristics and delirium subtypes may influence referral and should inform future liaison efforts.

Psychological and Social Factors that Correlate with Dyspnea in Heart Failure

Ramasamy, R., Hildebrandt, T., O'Hea, E., Patel, M., Clemow, L., Freudenberger, R., and Skotzko, C.

Psychosomatics, 47 (2006), 430–434.

Dyspnea is a common symptom of heart failure frequently relied upon to assess clinical functioning. The purpose of this study is to explore a broad range of medical, psychological, and social factors that correlate with dyspnea in heart failure patients. Seventy-six participants ranged from well-compensated, ambulatory subjects to those with recent hospitalization for acutely decompensated heart failure. The sample was predominantly male, mean age of 63.5 years, with mild depressive symptoms in 25%. Correlation analysis revealed that dyspnea significantly correlated with depression, fatigue, and overall health perception. Standard regression analyses indicated that depression, fatigue, and overall health perception uniquely contributed to dyspnea, explaining 38.0% of the total variance. The present study confirms that dyspnea is multifactorial, with links to psychological distress and overall health perception.

The Utility of Videoconferencing to provide Innovative Delivery of Psychological Treatment for Rural Cancer Patients: Results of a Pilot Study

Shepherd, L., Goldstein, D., Whitford, H., Thewes, B., Brummell, V., and Hicks, M.

Journal of Pain and Symptom Management, 32 (2006), 453–461.

The unmet psychological needs of rural cancer patients are numerous. Telepsychology is a novel and feasible option that may provide cost savings and help overcome inequalities in access to specialists. This is the first known study of psychological treatment for people with cancer delivered entirely via videoconferencing. We hypothesized that a telepsychology service would improve rural cancer patients' anxiety and depression levels and quality of life, and would be an acceptable, satisfactory, and practical mode of service delivery. Twenty-five cancer patients attended an average of three sessions with a clinical psychologist providing brief cognitive-behavioral therapy. Questionnaires were completed at pre-, post-, and 1-month follow-up. Patients benefited in terms of anxiety ($p = .01$) and quality of life ($p = .04$). The service was both practical and acceptable. These preliminary positive results provide a firm basis to conduct a randomized controlled trial of face-to-face interaction versus videoconferencing.

SYMPTOM CONTROL

Pain, Demographics, and Clinical Characteristics in Persons Who Received Hospice Care in the United States

Strassels, S.A., Blough, D.K., Hazlet, T.K., Veenstra, D.L., and Sullivan, S.D.

Journal of Pain and Symptom Management, 32 (2006), 519–531.

Pain in persons who receive hospice care is not fully understood. The purpose of this study was to describe the demographics, clinical characteristics, and pain intensity of persons who received hospice care in the United States from 2000 to 2004. Data for this study were obtained from a provider of hospice pharmacy services and included information about the hospice organization, demographics, and clinical characteristics, pain intensity, and opioid analgesic prescribing. Worst pain intensity during the previous 24 h was assessed using a 0–10 numeric rating scale (0 = none, 10 = worst) periodically during hospice care. During the study period, 347,555 persons received hospice services; 55.2% of these persons were

female, 87.4% were Caucasian, and mean age was 75.3 years. At least one pain score was available for 156,887 (45.1%) individuals. Among persons with at least one pain score, pain was reported a mean of 2.9 times per person. Overall, mean pain intensity was mild, but severe pain was reported at least once by 20.3% of persons. Of individuals who reported severe pain at least once, mean age was 68.9 years, 53.7% were female, 78.0% were Caucasian, 7.4% were cared for in long-term care hospices, and 73.9% had a primary diagnosis of cancer. Severe pain was reported at least once by a substantial percentage of persons in this study. These data provide insight into pain reported by persons who received hospice care, and may be useful as process indicators of the quality of care.

Opioid Use and Survival at the End of Life: A Survey of a Hospice Population

Portenoy R.K., Sibirceva U., Smout R., Horn S., Connor S., Blum R.H., Spence C., and Fine P.G.

Journal of Pain and Symptom Management, 32 (2006), 532–540.

Concern that opioids hasten death may be among the reasons that pain is treated inadequately in populations with advanced illness. Studies that assess the true risks are needed. To determine whether survival after last opioid dose change is associated with opioid dosing characteristics and other factors, data from the National Hospice Outcomes Project, a large prospective cohort study involving 13 U.S. hospice programs, were analyzed. Of 1306 patients, 725 received opioids and underwent at least one dose change before death. Subsamples based on maximum opioid dose compared patients receiving usual doses with those receiving high-dose therapy. Spearman rank correlations examined bivariate associations between survival after final dose change and other variables, including dose in morphine equivalent mg and percentage dose increase. Multivariate least squares regression analyses determined associations between survival and other variables, including those significant in bivariate analyses. The mean \pm SD number of days between final dose change and death was 12.46 ± 23.11 . Multivariate models demonstrated a significant association between shorter survival and higher opioid dose, a cancer diagnosis, unresponsiveness, and pain of <5 on a 0–10 scale, but none of these models explained $>10\%$ of the variance in time till death. Analyses of subsamples did not reveal additional effects of dose. This analysis revealed that opioid dosing was associated with time till death, but this factor would explain very little of the variation in

survival. In a hospice population, survival is influenced by complex factors, many of which may not be measurable. Based on these findings, concern about hastening death does not justify withholding opioid therapy.

A Randomized, Double-Blind, Crossover Trial of the Effect of Oxygen on Dyspnea in Patients with Advanced Cancer

Philip, J., Gold, M., Milner, A., Di Iulio, J., Miller, B., and Spruyt, O.

Journal of Pain and Symptom Management, 32 (2006), 541–550.

Dyspnea is a common symptom in palliative care. Despite this, there is uncertainty regarding the role of oxygen to treat the symptom in patients with advanced illness. This randomized, double-blind, crossover trial examined the effect of oxygen versus air on the relief of dyspnea in patients with advanced cancer. Following the blinded administration of air and oxygen via nasal prongs, 51 patients rated dyspnea and indicated preferences for the blinded treatments. On average, patients improved symptomatically with both air and oxygen, and there were no significant differences between the treatments. The subgroup of 17 hypoxic patients overall did not demonstrate a significant difference between air and oxygen, despite having improved oxygen saturations when administered oxygen. Hypoxia was corrected in 13 of 17 patients using the treatment dose of 4 L/min of oxygen. The experience of dyspnea is a complex, multifactorial phenomenon, with oxygen tension not correlating with the subjective experience. The administration of either air or oxygen via nasal prongs on average confers improvement of the symptom.

Symptom Experience in the Last Year of Life among Individuals with Cancer

Doorenbos, A.Z., Given, C.W., Given, B., and Verbitsky, N.

Journal of Pain and Symptom Management, 32 (2006), 403–412.

Individuals with cancer often experience many symptoms that impair their quality of life at the end of life. This study examines symptom experience at the end of life among individuals with cancer and determines if symptom experience changes with proximity to death or differs by depressive symptomatology, sex, site of cancer, or age. A secondary analysis of data from three prospective, descriptive, longitudinal studies ($n = 174$) was performed, using

a three-level hierarchical linear model. Fatigue, weakness, pain, shortness of breath, and cough were the five most prevalent symptoms in the last year of life. The symptom experience in the last year of life was significantly associated with site of cancer, depressive symptomatology, dependencies in activities of daily living, and independent activities of daily living at the start of the study. These findings shed light on the symptom experience in the last year of life for individuals with cancer. With greater understanding of the symptom experience, intervention strategies can be targeted to achieve the desired outcome of increased quality of life at the end of life.

Opioid Escalation in Patients with Cancer Pain: The Effect of Age

Mercadante, S., Ferrera, P., Villari, P., and Casuccio, A.

Journal of Pain and Symptom Management, 32 (2006), 413–419.

Elderly people are commonly considered more susceptible to opioid effects. However, no data regarding the need for opioid escalation in patients already receiving opioids for the management of chronic pain are available. The purpose of this study was to evaluate the differences between younger and older patients during the crucial phase of opioid titration. One hundred consecutive patients with cancer pain requiring further opioid dose refinement were recruited for this cohort study. Pain intensity, dose of opioids, number of opioids used (need to switch), routes of administration used, and opioid-related symptoms were measured from admission until dose stabilization. Opioid escalation indexes (OEIs) were calculated. For the purpose of analysis, patients were divided into three age groups (<65, 65–74, 75 or over). Despite differences in opioid doses at admission (lower in older patients), no differences were found in routes, need to switch, OEI, or other parameters between younger and older patients. Similarly, adverse effects did not significantly differ between the three groups, although an overall distress score worsened in older patients during acute titration and then improved at stabilization time. These data contradict the assumption that older patients who already receive opioids are more susceptible than younger adults to opioid effects during opioid titration. Although the elderly require lower doses, opioid effects do not appear to vary with age in this population. However, the group of patients over 75 was relatively small and data should be interpreted with caution. Careful titration based on the individual response seems appropriate irrespective of age.

Measuring Fatigue in Parkinson's Disease: A Psychometric Study of Two Brief Generic Fatigue Questionnaires

Hagell, P., Hoglund, A., Reimer, J., Eriksson, B., Knutsson, I., Widner, H., and Cella, D.

Journal of Pain and Symptom Management, 32 (2006), 420–432.

This study evaluated and compared the measurement properties of the 13-item Functional Assessment of Chronic Illness Therapy-Fatigue Scale (FACIT-F) and the 9-item Fatigue Severity Scale (FSS) in 118 consecutive Parkinson's disease (PD) patients, using traditional and Rasch measurement methodologies. Both questionnaires exhibited excellent data quality and reliability (coefficient alpha $\geq .9$), and acceptable rating scale functionality, and both discriminated between fatigued and nonfatigued patients. Factor and Rasch analyses provided general support for unidimensionality of both FACIT-F and FSS, although they do not appear to measure identical aspects of fatigue. No signs of differential item functioning (DIF) were found for the FACIT-F, whereas potential age DIF was detected for two FSS items. These results support the measurement validity of both questionnaires in PD, although the FACIT-F displayed better measurement precision and modest psychometric advantages over the FSS. Availability of psychometrically sound fatigue measures that are applicable across disorders provides a sound basis for advancing the understanding of this common and distressing complaint.

An Urban Community's Preferences for Hypothetical Outcomes of Analgesic Pain Treatment

Palos, G.R., Cantor, S.B., Aday, L.A., Mendoza, T.R., Mobley, G.M., and Cleeland, C.S.

Journal of Pain and Symptom Management, 32 (2006), 470–477.

We assessed preferences of urban residents regarding hypothetical treatment outcomes related to analgesic use to determine how well subjects understood the severity of the outcomes, describe community preferences for these outcomes, and identify predictors of preferences. In a cross-sectional telephone survey, we obtained mean ratings for hypothetical outcomes that included two dimensions of clinical pain (pain severity and potential side effects): A = moderate pain, three side effects; B = mild pain, three side effects; C = moderate pain, one side effect. We focused on 111 respondents who rated Outcome A, moderate pain with three side effects, as the worst condition (the logical choice).

Being Spanish speaking predicted preferences across treatment Outcomes A and B. Spanish-speaking subjects and those in fair to poor health tended to view all three outcomes more negatively than other respondents. Knowledge of public preferences can help clinicians better understand factors that influence treatment choices and may help them motivate their patients to adhere to analgesic regimens.

Genuine, Suppressed and Faked Facial Expressions of Pain in Children

Larochette, A.C., Chambers, C.T., and Craig, K.D.

Pain, 126 (2006), 64–71.

Children's efforts to hide or exaggerate facial expressions of pain were compared to their genuine expressions using the cold pressor task. Fifty healthy 8- to 12-year-olds (25 boys, 25 girls) submerged their hands in cold and warm water and were instructed about what to show on their faces. Cold 10°C water was used for the genuine and suppressed conditions and warm 30°C water was used for the faked condition. Facial activity was videotaped and coded using the Facial Action Coding System to provide objective, detailed accounts of facial expressions in each condition, as well as during a baseline condition. Parents were subsequently asked to correctly identify each of the four conditions by viewing each video clip twice. Faked expressions of pain in children were found to show more frequent and more intense facial actions compared to their genuine pain expression, indicating that children had some understanding but were not fully successful in faking expressions of pain. Children's suppressed expressions, however, showed no differences from baseline facial actions, indicating that they were able to successfully suppress their expressions of pain. Parents correctly identified the four conditions significantly more frequently than would be expected by chance. They were generally quite successful at detecting faked pain, but experienced difficulty differentiating among the other conditions. The results indicate that children are capable of controlling their facial expressions of pain when instructed to do so, but are better able to hide their pain than to fake it.

Pain Affects Spouses Too: Personal Experience with Pain and Catastrophizing as Correlates of Spouse Distress

Leonard, M.T. and Cano, A.

Pain, 126 (2006), 139–146.

Chronic pain has adverse effects on individuals with chronic pain (ICPs) as well as their family members.

Borrowing from an empathy model described by Goubert et al., we examined top-down and bottom-up factors that may be related to psychological well-being in the spouses of ICPs. A diverse community sample of 113 middle-aged spouses of individuals with chronic pain (ICPs) completed measures on pain severity and spouse pain catastrophizing (PCS-S). Results showed that almost half (48.7%) of spouses reported chronic pain themselves and that pain in the spouse accounted for within-couple differences on psychological distress. That is, in couples where only the ICP reported pain, ICP psychological distress was greater than in their spouses. However, when both partners reported chronic pain, there was no significant difference in psychological distress between partners. Hierarchical regression analyses showed that spouse magnification catastrophizing was associated with depressive and anxiety symptoms, and that helplessness catastrophizing was associated with depressive symptoms for spouses of ICPs who also reported chronic pain but not for spouses of ICPs without chronic pain. The results are discussed in light of interpersonal processes that may affect spouses' distress.

Pain Assessment in Profound Cognitive Impaired Children Using the Checklist Pain Behavior: Is Item Reduction Valid?

Duivenvoorden, H.J., Tibboel, D., Koot, H.M., van Dijk, M., and Peters, J.W.

Pain, 126 (2006), 147–154.

There are both commonalities and idiosyncratic features in the reaction of pain in children with profound cognitive impairment (CI), and there is no evidence to suggest that idiosyncratic behavior is more characteristic of this population than of any other population. The main objective of this study was to identify whether the 23-item version of the Checklist Pain Behavior could be reduced to 10 items. Previous research demonstrated that only these 10 items discriminated between absence and presence of pain. Second, we wanted to explore the underlying structure of these 10 selected items including its performance. Data of 477 observations in 73 children were used. All these children were videotaped while they were admitted to the Sophia Children's Hospital for surgery, twice before and five times after surgery. These videotapes were scored by an independent observer. A visual analogue scale (VAS) by a researcher was used to assess the presence of pain. We tested whether the underlying structure was unidimensional and whether it had differential qualities between pain and no pain and to what degree. Using a modern psychometric

method, that is, Mokken scaling model, we unraveled the interdependency of the pain response in CI children, in that the structure turned out to be unidimensional. In addition, these behaviors could be hierarchically ordered in terms of frequency of occurrences. Finally, these behaviors had to a high degree the potentialities to estimate the likelihood of occurrence of pain.

High Dose Controlled-Release Oxycodone in Hospice Care

Bercovitch, M., and Adunsky, A.

Journal of Pain & Palliative Care Pharmacotherapy, 20 (2006), 33–39.

Controlled-release oxycodone (OxyContin) is commonly used for pain relief in terminal cancer. This opioid may be considered as a treatment option for patients who prefer oral pain control, but who are unwilling to take oral morphine sulphate or cannot tolerate its side effects. However, little is documented about the use of high doses of this drug in terminal cancer patients. The purpose of this study was to investigate the clinical characteristics of terminally ill hospice inpatients treated with OxyContin for pain, and to compare those patients receiving high-dose OxyContin (150 mg/day) with patients taking low and more typical doses. This retrospective chart analysis with parallel groups included records of 97 consecutive terminal cancer patients. We recorded clinical and demographic data, as well as data regarding daily doses, rescue doses, and parameters associated with quality of life. The mean daily OxyContin dose was 78.6 mg per day for all patients. Only 18 (18.55%) patients were treated with high doses (mean daily dose 231.1 mg). No statistically significant correlations were found between any of the demographic parameters and dose ranges, with the exception of patients with painful bony metastases, who consumed significantly higher doses ($p = .008$). No differences were observed in sleep quality or mood as a factor of OxyContin doses. However, compared with patients receiving low-dose (OR 1.0), patients treated with moderate and high doses maintained Karnofsky scores higher than 40 points most of the time (OR = 3.77, CI 1.1–13.0 and OR 4.95, CI 0.8–29.9, respectively). Survival was not related to OxyContin doses (Log Rank test, $p = .12$; Breslow test, $p = .37$). We conclude that the use of high dose OxyContin for terminal cancer pain management is safe, efficient, and unrelated to shorter survival times. The results suggest that health care professionals may use higher OxyContin doses, when indicated, to enable better pain relief and quality end-of-life care.

QUALITY OF PALLIATIVE CARE

Factors Related to the Psychological Well-Being of Parents of Children with Leukemia in China

Lou, V.W.

Journal of Psychosocial Oncology, 24 (2006), 75–88.

This study investigates factors correlated with the psychological well-being of parents of children with leukemia in China. A survey with self-administered questionnaires was employed and a total of 31 caregivers were recruited from two children's hospitals in Shanghai. The study investigates factors from three different aspects in the context of childhood cancer: children's illness-related and demographic variables, demographic variables of the parents, and the parents' coping approaches. The findings show that parents are at risk of poor psychological well-being related to perceived unsatisfactory financial status and a lack of self-oriented coping approaches. The implications for social service provision are discussed.

The effect of a Web-Based, Patient-Directed Intervention on Knowledge, Discussion, and Completion of a Health Care Proxy

Cintron, A., Phillips, R., and Hamel, M.B.

Journal of Palliative Medicine, 9 (2006), 1320–1328.

The objectives of this study was to examine the effect of patient-directed electronic messages on health care proxy (HCP) use. We used a randomized control trial using an electronic message intervention to encourage patients to complete an HCP document. The setting was a general medical practice at a large tertiary care teaching institution. Participants included 912 patients aged older than 50. We reviewed online medical records (OMRs) to assess for discussion and documentation of HCPs and to collect information on patient characteristics. We surveyed participants to determine knowledge, discussion, and completion of HCPs. Four hundred thirty participants were randomized to the intervention group and 482 to the control group. Only 1 HCP discussion (intervention group) and only 10 new HCPs (4 in intervention group vs. 6 in control group, $p = .649$) were documented in the OMR. Among the 444 survey responders, 205 (46%) reported having an HCP, but only 74 (36%) of these had discussed the HCP with their doctors and only 9 (4%) had a documented HCP in the OMR. Patients in the intervention group were more likely to report knowledge of HCPs (adjusted risk ratio [RR] 1.07; 95% confidence interval [CI],

1.01–1.14) and having a plan to complete one in the future (adjusted RR 1.19; 95% CI, 1.05–1.36). This patient-directed intervention did not increase patient completion of an HCP but was associated with greater knowledge of an HCP and planning to complete one.

Parents' Reactions to Participating in Interviews about End-of-Life Decision Making

Michelson, K.N., Koogler, T.K., Skipton, K., Sullivan, C., and Frader, J.

Journal of Palliative Medicine, 9 (2006), 1329–1338.

Although in-depth interviewing is well suited to studying the sensitive topic of end-of-life decision making, no reports have been published assessing the effects on parents of participating in interviews regarding end-of-life decision making for critically ill children. Our aim was to examine the reactions of pediatric intensive care unit (PICU) patients' parents to interviews on end-of-life decision making for their child. We conducted semistructured interviews on end-of-life decision making with PICU patients' parents from two tertiary care PICUs. We approached 117 parents of 102 patients. Seventy-four parents (63%) of 69 patients participated. Forty-three parents (61%) described the interview as "a good experience," 20 (29%) as "a neutral experience," and 1 (1%) as "a bad experience." The parent who judged the interview negatively stated that, "It bothers me a little bit because my son is [out] there having difficulties and I'm in here and not out there." Fifty-four of 59 parents (92%) said they would participate in another similar interview. Most parents (92%) felt the medical community should continue research on end-of-life decision making. Themes identified from the responses included emotional reaction to the interviews, exposure to end-of-life decision-making issues, impact on parents' views, and impact on future end-of-life decision making. Parents' comments suggested that many perceived the interviews as beneficial. This study demonstrates the willingness of many parents of critically ill children to participate in study interviews regarding end-of-life decision making, a topic that most parents felt was important and warranted more research.

The Turning Point: Clinical Identification of Dying and Reorientation of Care

Jakobsson, E., Bergh, I., Gaston-Johansson, F., Stolt, C.M., and Ohlen, J.

Journal of Palliative Medicine, 9 (2006), 1348–1358.

Palliative care is increasingly organized within the setting of formal health care systems, but the demarcation has become unclear between, on the one hand, care directed at cure and rehabilitation and palliative care aimed at relief of suffering on the other. With the purpose to increase the understanding about the turning point reflecting identification of dying and reorientation of care, this study explores this phenomenon as determined from health care records of a representative sample ($n = 229$). A turning point was identified in 160 records. Presence of circulatory diseases, sporadic confinement to bed, and deterioration of condition had a significant impact upon the incidence of such a turning point. The time interval between the turning point and actual death ranged between 1 and 210 days. Thirty percent of these turning points were documented within the last day of life, 33% during the last 2–7 days, 19.5% during the last 8–30 days, 13% during the last 31–90 days, and 4.5% during the last 91–210 days of life. The time interval between the turning point and actual death was significantly longer among individuals with neoplasm(s) and significantly shorter among individuals suffering from musculoskeletal diseases. Perhaps this reflects a discrepancy between the ideals of palliative care and a misinterpretation of the meaning of palliative care in everyday clinical practice. The findings underscore that improvement in timing of clinical identification of dying and reorientation of care will likely favor a shift from life-extending care.

The Impact of Providing Symptom Management Assistance on Caregiver Reaction: Results of a Randomized Trial

Given, B., Given, C.W., Sikorskii, A., Jeon, S., Sherwood, P., and Rahbar, M.

Journal of Pain and Symptom Management, 32 (2006), 433–443.

This research evaluates the impact of a randomized clinical trial for lowering family members' reactions and increasing their involvement in assisting cancer patients undergoing chemotherapy to better manage their symptoms. The cognitive behavioral intervention was directed toward both the patient and family caregivers. At 10 weeks, caregivers who received the experimental intervention had significantly lower total reactions to assisting with symptoms and assisted with significantly fewer symptoms (linked to patient improvement in symptom severity) than caregivers receiving conventional care alone. Female caregivers receiving the intervention reported significantly lower reaction per symptom where assistance was provided compared to female caregivers in

the control group. Thus, the intervention did not increase caregiver involvement in symptom management, quite possibly due to reduced symptom severity among patients in the intervention group. This research offers a model for evaluating trials directed toward both members of a dyad.

SPIRITUALITY

Peaceful Awareness in Patients with Advanced Cancer

Ray, A., Block, S.D., Friedlander, R.J., Zhang, B., Maciejewski, P.K., and Prigerson, H.G.

Journal of Palliative Medicine, 9 (2006), 1359–1368.

Previous studies have shown that prognostic awareness may be harmful to mental health yet beneficial for end-of-life care planning. The effects of prognostic awareness coupled with a sense of inner peace are unknown. In the multisite, longitudinal Coping with Cancer Study, 280 patients with advanced cancer were interviewed at baseline. Patients defining themselves as “terminally ill” and/or “at peace” most days were paired with others on sociodemographic, mental health, and advance care planning. Primary caregivers of deceased patients were interviewed 6 months postloss and compared on their physical and mental health and their perceptions of patients’ end-of-life care and death. Overall, 17.5% of patients reported being both peaceful and aware. Peacefully aware patients had lower rates of psychological distress and higher rates of advance care planning (e.g., completing do-not-resuscitate orders, advance care planning discussions with physicians) than those who were not peacefully aware. Additionally, peacefully aware patients had the highest overall quality of death as reported by their caretakers in a postmortem evaluation. Surviving caregivers of peacefully aware patients were more physically and mentally healthy 6 months postloss than caregivers of patients who were “aware” but not peaceful. Patients with advanced cancer who are peacefully aware have better mental health and quality of death outcomes, and their surviving caregivers have better bereavement outcomes. Peaceful awareness is associated with modifiable aspects of medical care (e.g., discussions about terminal treatment preferences).

Existential Loneliness in a Palliative Home Care Setting

Sand, L., and Strang, P.

Journal of Palliative Medicine, 9 (2006), 1376–1387.

The diagnosis of an incurable disease implies an existential crisis. This study focused on the emotions, perceptions, and experiences of existential isolation in palliative patients with cancer and their families. A total of 40 respondents (20 patients and 20 family members) were interviewed in depth. All were Swedes who defined themselves as nonreligious. The patients were enrolled in an advanced hospital-based home care team. The interviews were taped, transcribed, and analyzed with a qualitative, hermeneutic method. The data revealed experiences of existential loneliness with the impending death as a primary source. Experiences of being alone in “a world of one’s own” were common. The changes in everyday life and the increasingly restricted social interaction because of the illness meant that the patient partly lost the protection against isolation that the spirit of community normally provides. Other situations that had triggered the existential isolation were, for example, when a patient in need of support was left alone, when he or she was treated disrespectfully or in a way that made him or her feel invisible, or when people avoided contact because of uneasiness or fear. Changes in one’s own body and mood gave rise to feelings of loneliness and unfamiliarity toward oneself. When a staff member touched the patient’s body in a nonempathic way, this could induce feelings of being treated like an animal.

COMMUNICATION

Bereaved Hospice Caregivers’ Perceptions of the End-of-Life Care Communication Process and the Involvement of Health Care Professionals

Csikai, E.L.

Journal of Palliative Medicine, 9 (2006), 1300–1309.

This study was conducted to gain an understanding of bereaved hospice family caregivers’ perceptions of the communication process from initial discussion of the need for end-of-life care and hospice through the decision to choose hospice and the transition home. One hundred eight bereaved hospice caregivers that were 36 months postpatient death responded to a quantitative mailed survey. Aspects of the end-of-life care communication process, including involvement of health care professionals at each step, were assessed. Serious illness and the need for hospice care were first mentioned to patients and caregivers by physicians. Often the caregivers recalled only one meeting in which hospice was discussed. Other than the physicians,

social workers were the professionals most often present in at least one of these meetings. Nurses and social workers were both perceived to be helpful in the transition to home hospice. Social workers were reported to be most comfortable with discussion of end-of-life care, most knowledgeable, and most available during the communication process that led to a decision about end-of-life care. Suggestions that these caregivers had to improve communication with health care professionals were categorized from responses to an open-ended survey

question such as the need to discuss vital information earlier and what to expect for care at end stage, be more forthcoming about reality of death, and treat people as individuals. Although many health care professionals play a role in the communication and transition to hospice care, physicians and social workers were found to be pivotal participants in this process. A coordinated team approach to end-of-life communication and decision making may facilitate the process and possibly lead to increased and earlier referral to hospice.