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Clinical Update: Literature Abstracts

NEW MEASURES

Family Reports of Dying Patients' Distress: The Adaptation of a Research Tool to Assess Global Symptom Distress in the Last Week of Life

Hickman, S.E., Tilden, V.P., and Tolle, S.W.

Journal of Pain Symptom Management, *22* (2001), 565–574

Understanding dying patients' symptom distress is an important component of efforts to improve care at the end of life. It can, however, be difficult to conduct research with dying patients; often, family members can serve as sources of information about decedents' last days of life. In order to assess family reports of decedents' global symptom distress in the last week of life, the authors adapted the Memorial Symptom Assessment Scale Global Distress Index (MSAS-GDI), a brief measure of patient global symptom distress, for use in a retrospective study of family reports about end-of-life care. It was administered to a sample of 103 family members to assess the psychometric properties of the instrument in bereaved family members. The Family MSAS-GDI consists of questions about 11 psychological and physical symptoms commonly experienced by dying patients. The majority of family members were able to respond to the scale items. The mean Family MSAS-GDI score was 1.14 (SD = 0.87) with a range of 0 to 3.73. The scale demonstrated good internal consistency (α = 0.82). The average item-total correlation was r = 0.49 and the average inter-item correlation was r = 0.30, suggesting items were moderately correlated with the overall total scale and with each other. The Family MSAS-GDI could prove to be a useful tool in assessing and tracking global symptom distress in dying patients.

A Scale for Measuring Patient Perceptions of the Quality of End-of-Life Care and Satisfaction with Treatment: The Reliability and Validity of QUEST

Sulmasy, D.P., McIlvane, J.M., Pasley, P.M., and Rahn, M.

Journal of Pain Symptom Management, *23* (2002), 458–470

We report on the adaptation and evaluation of a previously developed patient-centered instrument that we call the Quality of End-of-life care and Satisfaction with Treatment (QUEST) scale. In a group of 30 inpatients, test–retest reliability for QUEST items ranged from 63% agreement (kappa = 0.43) to 93% agreement (kappa = 0.86) and construct validity was evidenced by correlations with a somewhat related satisfaction scale ranging from 0.38 to 0.47. The QUEST was then administered to 206 consecutive medical inpatients (or their surrogates) with DNR orders and to a comparison group of 51 medical inpatients without DNR orders at two academic medical centers. Among these study patients, internal consistency was reflected by Cronbach alphas of 0.88 to 0.93. QUEST scores showed modest inverse correlations with severity of symptoms, but were uncorrelated with severity of illness, anxiety, or depression, suggesting an appropriate relationship to symptom control but divergence of the underlying construct from degree of physical illness or affective state. The QUEST scores were lower for patients with DNR orders compared to those without DNR orders (P = 0.02 to 0.06). Surrogate ratings of satisfaction and quality were uncorrelated with patient ratings. Although preliminary, these findings suggest that QUEST may be useful in assessing quality and satisfaction with the care rendered by physicians and nurses to hospitalized patients at the end of life.

A Measure of the Quality of Dying and Death: Initial Validation Using After-Death Interviews with Family Members

Curtis, J.R., Patrick, D.L., Engelberg, R.A., Norris, K., Asp, C., and Byock, I.

Journal of Pain Symptom Management, *24* (2002), 17–31

A reliable and valid measure of the quality of the dying experience would help clinicians and researchers improve care for dying patients. To describe the validity of an instrument assessing the quality of dying and death using the perspective of family members after death and to identify clinical correlates of a high quality death, a retrospective cohort study evaluated the 31-item Quality of Dying and Death (QODD) questionnaire. The questionnaire was administered to family members of patients who died in Missoula County, Montana in 1996 and 1997. The interview included questions assessing symptoms, patient preferences, and satisfaction with care. Measurement validity was examined for item and total scores and reliability analyses for the QODD total score were assessed. Construct validity was assessed using measures of concepts hypothesized to be associated with the quality of dying and death. There were 935 deaths, of which 252 (27.0%) family interviews were represented. Nonenrolled decedents were not significantly different from enrolled decedents on age, sex, cause of death, or location of death. We excluded sudden deaths ($n = 45$) and decedents under age 18 ($n = 2$), leaving 205 after-death interviews. A total QODD score, on a scale from 0 to 100 with higher scores indicating better quality, ranged from 26.0 to 99.6, with a mean of 67.4 and Cronbach's alpha of 0.89. The total QODD score was not associated with patient age, sex, education, marital status, or income. As hypothesized, higher QODD scores were significantly associated with death at home ($P < 0.01$), death in the location the patient desired ($P < 0.01$), lower symptom burden ($P < 0.001$), and better ratings of symptom treatment ($P < 0.01$). Although the total score was not associated with the presence of an advance directive, higher scores were associated with communication about treatment preferences ($P < 0.01$), compliance with treatment preferences ($P < 0.001$), and family satisfaction regarding communication with the health care team ($P < 0.01$). Availability of a health care team member at night or on weekends was also associated with a higher QODD score ($P < 0.001$). The QODD total score demonstrated good cross-sectional validity. Future work will assess the potential role of the QODD in improving the quality of the dying experience.

The System of Belief Inventory (SBI-15): A Validation Study in Israel

Baider, L., Holland, J.C., Russak, S.M., and Kaplan De-Nour, A.

Psycho-Oncology, *10* (2001), 543–540

This study focused on the validation of measures assessing religiosity by means of three self-report instruments: The System of Belief Inventory (SBI-15R), the Religious Orientation Inventory (ROI) and the Index of Core Spiritual Experiences (INSPIRIT). These instruments were developed and validated previously in the United States. The study measured the extent to which the self-reports maintain their validity when administered in a different country with its own distinct language, culture and religion (e.g., Israel). It was found that all three self-reports have very good external validity and high convergent reliability, with the SBI demonstrating extremely high internal reliability.

The Daily Spiritual Experience Scale: Development, Theoretical Description, Reliability, Exploratory Factor Analysis, and Preliminary Construct Validity Using Health-Related Data

Underwood, L.G. and Teresi, J.A.

Annals of Behavioral Medicine, *24* (2002), 22–33

This paper describes the Daily Spiritual Experience Scale (DSES) and its development, reliability, exploratory factor analyses, and preliminary construct validity. Normative data from random samples and preliminary relationships of health-related data with the DSES are also included. Data for the 16-item DSES are provided from two studies; a third study provided data on a subset of 6 items, and a fourth study was done on the interrater reliability of the item subset. A 6-item version was used in the General Social Survey because of the need to shorten the measure for the survey. This scale addresses reported ordinary experiences of spirituality such as awe, joy that lifts one out of the mundane, and a sense of deep inner peace. Studies using the DSES may identify ways in which this element of life may influence emotion, cognition, behavior, and health. The DSES demonstrates good reliability and internal consistency. Preliminary evidence showed that daily spiritual experience is

related to decreased total alcohol intake, improved quality of life, and positive psychosocial status.

SYMPTOM CONTROL

An Open-Label, Crossover Trial of Mirtazapine (15 and 30 mg) in Cancer Patients with Pain and Other Distressing Symptoms

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Journal of Pain Symptom Management, *23* (2002), 442–447

The investigators performed a pilot open-label, crossover trial of mirtazapine (15 and 30 mg at night) in advanced cancer patients with pain and other distressing symptoms. Twenty patients completed the trial and sixteen dropped out. Following a baseline assessment, patients completed a one-week observation period and were then randomized to a starting dose of either 15 mg or 30 mg of mirtazapine given at bedtime. After three weeks, subjects were switched to the alternate dose and followed by an additional three-week period, completing the treatment. The average age of the completers was 60.2 years and consisted of 7 women and 13 men. The majority were Caucasian ($n = 18$, 90%) and married ($n = 18$, 90%). The drop-out group did not significantly differ from the completers based on age, gender, race, marital status, or tumor type. We examined the impact of mirtazapine therapy on patients' levels of depression, pain intensity, appetite, insomnia, weight, and overall quality of life. A series of repeated measures ANOVAs were conducted to compare the completers' status at Weeks 1, 4, and 7 compared to baseline and to examine the interaction with starting dose and baseline observations. Scores on the Zung self-rating Depression Scale ($F = 8.20$, $P < 0.05$) and the Functional Assessment of Cancer Therapy—General Measure ($F = 5.73, P < 0.05$) were significantly improved at study end (Week 7) and were not dependent on mirtazapine dosage. Patients' weights were significantly higher at both Week 4 and Week 7, independent of dosage. Trend level differences were found on Memorial Pain Assessment Card items for pain, pain relief, and mood and on numeric rating scales measuring nausea, anxiety, insomnia, and appetite. This open-label pilot study suggests that mirtazapine may be effective for improving multiple symptoms, depression, and quality of life in patients with advanced cancer. A controlled trial of this drug would be valuable.

The Delirium Experience: Delirium Recall and Delirium-Related Distress in Hospitalized Patients with Cancer, Their Spouses/Caregivers, and Their Nurses

Breitbart, W., Gibson, C., and Tremblay, A.

Psychosomatics, *43* (2002), 183–194

We conducted a systematic examination of the experience of delirium in a sample of 154 hospitalized patients with cancer. Patients all met DSM-IV criteria for delirium and were rated with the Memorial Delirium Assessment Scale as a measure of delirium severity, phenomenology, and resolution. Of the 154 patients assessed, 101 had complete resolution of their delirium and were administered the Delirium Experience Questionnaire (DEQ—a face-valid measure that assesses delirium recall and distress related to the delirium episode). Spouse/caregivers and primary nurses were also administered the DEQ to assess distress related to caring for a delirious patient. Fifty-four (53.5%) patients recalled their delirium experience. Logistic-regression analysis demonstrated that short-term memory impairment (odds ratio [OR] = 38.4), delirium severity (OR = 11.3), and the presence of perceptual disturbances (OR = 6.9) were significant predictors of delirium recall. Mean delirium-related distress levels (on a 0–4 numerical rating scale of the DEQ) were 3.2 for patients who recalled delirium, 3.75 for spouses/caregivers, and 3.09 for nurses. Logistic-regression analysis demonstrated that the presence of delusions (OR = 7.9) was the most significant predictor of patient distress. Patients with "hypoactive" delirium were just as distressed as patients with "hyperactive" delirium. Karnofsky Performance Status (OR = 9.1) was the most significant predictor of spouse/caregiver distress. Delirium severity (OR = 5.2) and the presence of perceptual disturbances (OR = 3.6) were the most significant predictors of nurse distress. In conclusion, a majority of patients with delirium recall their delirium as highly distressing. Delirium is also a highly distressing experience for spouses/caregivers and nurses who are caring for delirious patients. Prompt recognition and treatment of delirium is critically important to reduce suffering and distress.

An Open Trial of Olanzapine for the Treatment of Delirium in Hospitalized Cancer Patients

Breitbart, W., Tremblay, A., and Gibson, C.

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We conducted an open, prospective trial of olanzapine for the treatment of delirium in a sample of

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79 hospitalized cancer patients. Patients all met DSM-IV criteria for a diagnosis of delirium and were rated systematically with the Memorial Delirium Assessment Scale (MDAS) as a measure of delirium severity, phenomenology, and resolution, over the course of a 7-day treatment period. Sociodemographic and medical variables and measures of physical performance status and drug-related side effects were collected. Fifty-seven patients (76%) had complete resolution of their delirium on olanzapine therapy. No patients experienced extrapyramidal side effects; however, 30% experienced sedation (usually not severe enough to interrupt treatment). Several factors were found to be significantly associated with poorer response to olanzapine treatment for delirium, including age greater than 70 years, history of dementia, central nervous system spread of cancer and hypoxia as delirium etiologies, "hypoactive" delirium, and delirium of "severe" intensity (i.e., MDAS $>$ 23). A logistic-regression model suggests that age greater than $>$70 years is the most powerful predictor of poorer response to olanzapine treatment for delirium (odds ratio, 171.5). Olanzapine appears to be a clinically efficacious and safe drug for the treatment of the symptoms of delirium in the hospitalized medically ill.

Preliminary Evaluation of a Clinical Syndrome Approach to Assessing Cancer-Related Fatigue

Sadler, I.J., Jacobsen, P.B., Booth-Jones, M., Belanger, H., Weitzner, M., and Fields, K.K.

Journal of Pain Symptom Management, *23* (2002), 406–416

The objectives of this study were to evaluate the reliability, validity, and utility of a newly developed clinical syndrome approach to assessing cancer-related fatigue. Fifty-one patients who underwent blood or marrow transplantation an average of 6.9 months previously were administered a standardized interview designed to identify the presence of a clinical syndrome of cancer-related fatigue. Patients also completed self-report measures of fatigue, depression, and health-related quality of life. Comparisons among independent raters demonstrated high rates of reliability for the presence or absence of a cancer-related fatigue syndrome and its symptoms. Twenty-one percent of patients (n = 11) were found to meet criteria for diagnosis of a cancer-related fatigue syndrome. Compared to patients not meeting the diagnostic criteria, patients meeting the criteria reported fatigue that was greater ($P \leq 0.05$) in its severity, frequency, pervasiveness, and interference with quality of life. Patients who met criteria also demonstrated poorer role functioning, less vitality, and more depressive symptomatology ($P \leq 0.05$). These findings provide preliminary evidence of the reliability and validity of the methods used to assess the proposed clinical syndrome and suggest their utility in identifying patients experiencing clinically significant cancer-related fatigue.

Predicting the Trajectory of Will to Live in Terminally Ill Patients

Tataryn, D. and Chochinov, H.

Psychosomatics, *43* (2002), 370–377

Will to live has been demonstrated to vary considerably during the final period of a terminal illness. The goal of this study was to identify illness-related and demographic variables predicting will to live among dying patients. Subjects were 168 patients with cancer who were admitted for palliative care. Will to live was measured twice daily for the duration of hospitalization by using a self-report 100-mm visual analogue scale. Will-to-live data for each patient were summarized into two statistics, intercept and slope, by using simple linear regression analyses. Intercept-slope pairs for all patients were classified into the following five clusters by using spatial and conceptual criteria: patients with sustained high will to live (58%), patients with sustained moderate will to live (11%), patients with sustained low will to live (3%), will-to-live relinquishers (18%), and will-to-live acquirers (10%). Discriminant analyses revealed seven variables that accounted for 69% of the variance in cluster membership: anxiety, shortness of breath, nausea, length of survival from time of admission, having a diagnosis of colon cancer, having no religion, and living with a spouse.

Demoralization Syndrome—A Relevant Psychiatric Diagnosis for Palliative Care

Kissane, D.W., Clarke, D.M., and Street, A.F.

Journal of Palliative Care, *17* (2001), 12–21

Existential distress and despair, hopelessness, and loss of meaning have been recognized as symptoms in palliative care that can be easily confused with depression. In this article, the authors propose a new syndrome, the demoralization syndrome, which they define as a psychiatric state in which helplessness, helplessness, meaningless, and existential distress are the core phenomena. The authors discuss the literature of demoralization, differentiating demoralization and depression, demoralization and disability, treatment options for demoralization, and demoralization and the choice to die, and conclude

that demoralization syndrome has utility as a diagnostic category in palliative care.

Preferences for Palliative Sedation Therapy in the Japanese General Population

Morita, T., Hirai, K., and Okazaki, Y.

Journal of Palliative Medicine, *5* (2002), 375–385

To elucidate which types of palliative sedation therapy are preferred by the Japanese general population, what factors influence these preferences, and how the general population thinks clinicians should inform patients about sedation therapy, the investigators conducted a cross-sectional questionnaire survey using a convenience sample of 457 Japanese people (effective response rate, 53.2%). For refractory intractable physical distress, intermittent deep sedation was chosen as "probably want" or "strongly want" by 86% of the respondents, and mild sedation was chosen by 82%. For refractory intractable psychological distress, intermittent deep sedation was chosen as "probably want" or "strongly want" by 76%, and mild sedation was chosen by 68%. Continuous deep sedation was chosen as "absolutely not want" or "probably not want" by 72% for physical distress and 71% for psychological distress. The respondents who did not want continuous deep sedation were significantly younger, more educated, and more likely to perceive the importance of dignity and preparation for death. Eighty-five percent wanted clear information about reduction in consciousness, and 92% were positive with "in advance" information about sedation therapy. When family members did not agree with the patient's decision, 71% stated that physicians should follow the patient's wishes.

The Japanese general population preferred intermittent deep or mild sedation to continuous deep sedation in alleviation of intractable and refractory distress. Many required explicit information about the serious consequences of sedation and wanted physicians to respect their wishes.

Effects of High-Dose Opiods and Sedatives on Survival in Terminally Ill Cancer Patients

Morita, J., Tsunoda, J., Inoue, S., and Chihara, S.

Journal of Pain Symptom Management, *21* (2001), 282–289

Concerns that high-dose opiods and sedatives might shorten patient survival could contribute to insufficient symptom alleviation for terminally ill cancer patients. To examine the effects on patient survival, of opiods and sedatives prescribed in the final 48 hours, a reanalysis of the prospectively collected data was performed on 209 hospice inpatients. Patient characteristics and clinical symptoms were prospectively recorded, and information about the use of opiods and sedatives in the last two days was collected by a chart review. Opiods were prescribed in 82% of the patients, with a median dose of 80 mg. Oral morphine equivalent (OME)/48 hours. Sixty percent received some sedative medications, mainly haloperidol (43% of total sample, 7.5 mg/48 hours), midazolam (24%, 23 mg/48 hours), and hydroxzine (15%, 50 mg/48 hours). There were no significant differences in survival between the patients who received different doses of opiods ($<$240, 240–599, and $\geqq$ 600 mg OME/48 hours) and of benzodiazepenes (0, 1–59, and $\geqq$ 60 mg parental midazolam equivalent/48 hours). Also, the survival of patients with haliperidol, hydroxyzxine, and other sedative medications did not differ from those without. Furthermore, an addition of use of opiods and sedatives in the final 48 hours in the multiple regression model for survival prediction achieved no significant increase in predictability. In conclusion, opiods and sedatives used for symptoms control in the last days are not associated with patient survival. They are safe and useful medications to palliate severe distress in the terminal stage of cancer when administered with a low initial dosage and adequate titration.