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## November 2007 Article of the Month

This month's article selection is by Chaplain John Ehman,  
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Murray, S. A., Kendall, M., Grant, E., Boyd, K., Barclay, S. and Sheikh, A. "**Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure.**" *Journal of Pain and Symptom Management* 34, no. 4 (October 2007): 393-402.

**SUMMARY and COMMENT:** This report of qualitative longitudinal research with lung cancer and heart failure patients identifies prevalent trajectories in social, psychological, and spiritual experiences that follow from physical declines in end-stage disease. Such research attempts to build a "big picture"--a broad perspective--to help providers understand and anticipate the potential needs of individuals, especially since the *pattern* of physical, social, psychological, and spiritual needs may form a complex interplay. Chaplains should find this work thought-provoking and valuable in its observations of how spiritual well-being may be in or out of sync with other aspects of illness at the end of life.

The researchers analyzed data from 112 in-depth interviews from 48 patients with advanced disease from southeast Scotland, collected through two separate but similar studies in 2000-2001 and 2002-2003. In each study, a social scientist conducted successive interviews with participants in their homes, asking them to talk about the main issues that they were facing generally; though in the second study spiritual issues were given special attention. Qualitative analysis was guided by a "multidisciplinary steering group," which included members with "medical, nursing, social work, and theological backgrounds" [p. 395]. It is worth noting that the authors construe the concept of *spirituality* very broadly, to encompass patients' explicitly theological/religious expressions as well as what might be characterized as existentialist concerns.

Results are presented as narrative summaries, with quotes from patients, for each of the four domains (i.e., physical, social, psychological, and spiritual) and for each of the two patient groups (i.e., lung cancer patients and heart failure patients). The descriptions are succinct and telling [--see pp. 396-399], but the authors have gone further and created graphic representations of the findings [--see pp. 397 and 398]: these are not intended to be formal graphs of hard data points, but helpful renderings of the insights gained from the research (and, for this reader, the ability to refer to these illustrations clarified not only the domain-specific patterns but their overall relation to one another as they formed a *multidimensional* pattern for each patient group).

By displaying all four dimensions of need graphically, we created an image to help us describe and contrast common patterns of well-being and distress experienced by people with advanced lung cancer and heart failure along a timeline. We did not attempt to measure levels of distress using a formal rating scale as these were qualitative studies of patient perceptions.

These two graphic illustrations that appear in the article are also part of a presentation by the authors to the Ninth Australian Palliative Care Conference (APCC), held in Melbourne on August 28-31, 2007 --publicly

available on the Internet as a [PDF](#)

Particular results: For lung cancer patients, social well-being declined with physical well-being in a general drop-off pattern. [See the [figure](#), in color, as it appears in the APCC presentation noted above.] The social decline appears to be determined largely by the disruptive effects of chemotherapy and by the social dynamics of stigma. Spiritual well-being and psychological well-being, however, track along side one another in a different trajectory of "distress at four key stages or transitions: diagnosis, discharge after treatment, disease progression, and the terminal stages" [p. 397]. These four common low points in the patient experience indicate needs for special support. (The authors note that other research has identified diagnosis, disease progression, and the terminal stage as low points, but the current research adds the point of *discharge after treatment* as a new finding [--see p. 400].) For the spiritual domain, the terminal phase of the disease may be a critical juncture, with some patients then experiencing a continual spiritual decline while some may experience an increase in spiritual well-being due to acceptance of death, confidence in faith, and an understanding of death as "a transition rather than the end" [p. 398].

For heart failure patients, declines in social well-being and psychological well-being both tend to follow the trajectory of physical decline that is marked by periodic crises in exacerbations. [See the [figure](#), in color, as it appears in the APCC presentation noted above.] The spiritual domain, though, tended to track independently, as "[s]piritual distress fluctuated more and was modulated by various other influences, including the perceived lack of understanding of these issues by health professionals..." [p. 399]. The role of "progressive loss of identity and growing dependence" [p. 399] are also named as critically affecting spiritual needs.

The authors address the limits of the research [--see p. 399] but see in their findings good evidence to support a practice of care planning that looks at all four dimensions of patient experience they have tracked, to be informed by a sense of the multidimensional trajectories of patient groups.

Typical trajectories may exist for other common diseases. Being aware of these trajectories may help clinicians anticipate times of increased social, psychological, and existential distress, and think proactively about ways of preventing or minimizing distress in their quest to help patients achieve a death with dignity. [p. 400]

They emphasize the opportunity to anticipate patients' needs for *education* that can be empowering. They also mention the importance of physician referrals to "social and spiritual care providers if the patient wishes" [p. 400].

This is a well-written presentation, enhanced by the authors' decision to graphically illustrate their qualitative findings and punctuated by cogent descriptions of patient experience. Though the article's target audience does not appear to be American, the authors are attentive to some statistics relevant to the US context, and there is no obvious problem in generalizing the results beyond the study's Scottish population. The bibliography includes 47 references. This work calls for replication, and chaplain researchers should consider such a project.

### **Suggestions for the Use of the Article for Discussion in CPE:**

This month's article could be discussed a number of ways with CPE students. First, and most obviously, it could be used to focus on the end-of-life experiences of lung cancer and heart failure patients, and chaplains' insights about spiritual trajectories could be paired with those of a guest physician or nurse specialist, with whom there could be an expanded discussion of multidimensional assessments of patients' needs. Second, students could be asked to think about the tension between a desire to concentrate on the individuality of each patient and the value of understanding general patterns of patient experience. In what ways might the microscopic and the macroscopic perspectives on patient experience each alone be a help or hindrance to patient care, and how might those perspectives be combined practically to gain the benefits of both? Third, students--even those with only a few months of clinical work--could be further challenged to think how they *already* may be operating

from a sense of the trajectories of certain patient populations in order to understand and anticipate needs and make pastoral plans. As an assignment, for follow-up discussion, ask each student to pick a patient population with which he/she is familiar and illustrate graphically how they believe that population tends to follow some common pattern of experience. They could then read more about disease trajectories, and examples from the literature are noted in Related Items of Interest (below). Fourth, the article could be examined as an example of qualitative research, paying special attention to the Methods section [--see pp. 394-396]. Fifth, the authors mention the concept of "dignity-preserving end-of-life-care" [p. 400]. Discussing that concept could be a productive tangent to explore. See the work by Chochinov in Related Items of Interest (below).

## Related Items of Interest:

I. The following articles use the concept of *trajectories* to look at the interplay of spirituality and health:

Davidson, P. M., Dracup, K., Phillips, J., Daly, J. and Padilla, G. "**Preparing for the worst while hoping for the best: the relevance of hope in the heart failure illness trajectory.**" *Journal of Cardiovascular Nursing* 22, no. 3 (May-June 2007): 159-165. [(From the abstract:) ...AIM: To explore the role of hope in heart disease and the potential utility of this construct in the development of nursing interventions. METHODS: The electronic databases CINAHL, MEDLINE, EmBASE, and PSYCHlit were searched from 1982 to August 2004 using the key words "hope," "hopelessness," "heart disease," and "heart failure." Articles were subsequently sorted to meet the inclusion criteria of (1) a philosophical discussion of the construct of hope and/or (2) investigation of hope in heart disease. RESULTS: This search retrieved 768 articles, and 24 met the inclusion criteria. Key findings from the review indicate that "hope" and "hopelessness" are underdeveloped, yet important constructs and conceptually linked with depression and spirituality. Intriguing findings from descriptive, observational studies have demonstrated the positive impact of expression of hope on cardiovascular outcomes.... (82 references)]

[ADDED 6/10/12]: Gall, T. L., Guirguis-Younger, M., Charbonneau, C. and Florack, P. "**The trajectory of religious coping across time in response to the diagnosis of breast cancer.**" *Psycho-Oncology* 18, no. 11 (Nov 2009): 1165-1178. [(Abstract:) OBJECTIVES: This study investigates the mobilization of religious coping in women's response to breast cancer. METHODS: Ninety-three breast cancer patients and 160 women with a benign diagnosis participated. Breast cancer patients were assessed on their use of religious coping strategies and their level of emotional distress and well-being at pre-diagnosis, 1 week pre-surgery, and 1 month, 6 months, 1 year, and 2 years post-surgery. RESULTS: In general, breast cancer patients used religious strategies more frequently than women with a benign diagnosis; however, the patterns of use were similar across time for the majority of strategies. Results showed that religious coping strategies are mobilized early on in the process of adjustment to breast cancer. Breast cancer patients' use of support or comfort-related strategies peaked around surgery and then declined, while the use of strategies that reflected more a process of meaning-making remained elevated or increased into the long-term. Positive and negative forms of religious coping were predictive of concurrent distress and emotional well-being. As well, there was evidence that the mobilization of religious coping was predictive of changes in distress and well-being across time. For example, women's increased use of active surrender coping from 1 to 6 months post-surgery was related to a concomitant decrease in emotional distress and increase in emotional well-being. CONCLUSIONS: Notably the nature of the relationship between religious coping and emotional adjustment depended on the type of religious coping strategy as well as the specific time of assessment. Specificity of information in the use of religious coping can allow health-care professionals to better identify resources and address potential points of difficulty during the process of women's adjustment to breast cancer.]

Highfield, M. F. "**Spiritual assessment across the cancer trajectory: methods and reflections.**" *Seminars in Oncology Nursing* 13, no. 4 (November 1997): 237-241. [This article focuses on the

idea of spiritual assessment but does so in light of the patient experience of cancer, as illustrated by a patient story. In doing so, the author presents a *de facto* spiritual trajectory, summarized in through nine key words: Bright, Plight, Fright, Flight, Night, Light, Fight, Sight, and Right (--see the table on p. 239).]

Holley, J. L. "**Palliative care in end-stage renal disease: illness trajectories, communication, and hospice use.**" *Advances in Chronic Kidney Disease* 14, no. 4 (October 2007): 402-408. [This review of the literature on End-Stage Renal Disease (ESRD) describes the illness trajectory of "a progressive decline punctuated by episodes of acute deterioration prompted by sentinel events like limb amputation or myocardial infarction" and emphasizes "opportunities for advance-care planning and communication between providers and patients and families" (p. 402, abstract). The authors recognize the role of spiritual support in palliative care.]

[ADDED 6/10/12]: Murray, S. A., Kendall, M., Boyd, K., Grant, L., Highet, G. and Sheikh, A. "**Archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family care givers of patients with lung cancer: secondary analysis of serial qualitative interviews.**" *BMJ [British Medical Journal]* 340 (2010): c2581 [electronic journal article/page designation]. [(Abstract:) OBJECTIVE: To assess if family care givers of patients with lung cancer experience the patterns of social, psychological, and spiritual wellbeing and distress typical of the patient, from diagnosis to death. DESIGN: Secondary analysis of serial qualitative interviews carried out every three months for up to a year or to bereavement. SETTING: South east Scotland. PARTICIPANTS: 19 patients with lung cancer and their 19 family carers, totalling 88 interviews (42 with patients and 46 with carers). RESULTS: Carers followed clear patterns of social, psychological, and spiritual wellbeing and distress that mirrored the experiences of those for whom they were caring, with some carers also experiencing deterioration in physical health that impacted on their ability to care. Psychological and spiritual distress were particularly dynamic and commonly experienced. In addition to the "Why us?" response, witnessing suffering triggered personal reflections in carers on the meaning and purpose of life. Certain key time points in the illness tended to be particularly problematic for both carers and patients: at diagnosis, at home after initial treatment, at recurrence, and during the terminal stage. CONCLUSIONS: Family carers witness and share much of the illness experience of the dying patient. The multidimensional experience of distress suffered by patients with lung cancer was reflected in the suffering of their carers in the social, psychological, and spiritual domains, with psychological and spiritual distress being most pronounced. Carers may need to be supported throughout the period of illness not just in the terminal phase and during bereavement, as currently tends to be the case.]

Murray, S. A., Kendall, M., Boyd, K. and Sheikh, A. "**Illness trajectories and palliative care.**" *BMJ: British Medical Journal* 330, no. 7498 (April 30, 2005): 1007-1011. [This review by four of the six authors of our featured article looks at the concept of trajectories in general in medical care, including their limitations (--see p. 1010). Examples are given for the conditions of cancer, organ failure, and frailty, and for the trajectories characterized by short periods of evident decline, long-term limitations with intermittent serious episodes, and prolonged dwindling. Spirituality is addressed briefly on p. 1010.]

Pelaez-Ballestas, I., Romero-Mendoza, M., Ramos-Lira, L., Caballero, R., Hernandez-Garduno, A. and Burgos-Vargas, R. "**Illness trajectories in Mexican children with juvenile idiopathic arthritis and their parents.**" *Rheumatology* 45, no. 11 (November 2006): 1399-1403. [This qualitative study out of Mexico looked at the experiences of 16 adults and 6 children from 10 families where there was incidence of juvenile idiopathic arthritis. Of special interest is the finding that the concept of "pilgrimage" was a major theme. See, under Results, the sections: Pilgrimage in Children, Pilgrimage in Parents, Pilgrimage in the Pre-Diagnosis Stage, and Pilgrimage in the Pre-Diagnosis Stage (pp. 1400-1401), as well as the Discussion section (p. 1402). "Pilgrimage was consistent with the model of the illness trajectory theory, which conceptually relates to the idea that the course of chronic diseases is variable and modifiable throughout time" (p. 1399, abstract).]

Wilkins, K. L. and Woodgate, R. L. "**An interruption in family life: siblings' lived experience as they transition through the pediatric bone marrow transplant trajectory.**" *Oncology Nursing Forum--Online* 34, 2 (March 2007): E28-35. [This Canadian study used semi-structured open-ended interviews with 8 siblings of pediatric bone marrow transplant (BMT) recipients to examine the sibling experience through the BMT trajectory. The article describes the BMT trajectory but focuses on the experience of interruption of the family. A theme of "faith in God that things will be okay" is detailed on pp. E32-33 and again on p. E34. The authors purport to show the value of hermeneutic phenomenology as a methodology.]

**II.** The authors of our featured article reference Harvey Max Chochinov's 2005 work, "Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life." Below is the reference to that article, along with notations of his subsequent work relating to dignity and spirituality:

Chochinov, H. M. "**Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care.**" *BMJ: British Medical Journal* 335, no. 7612 (July 28, 2007): 184-187. [The author presents a framework for health care that is "dignity preserving," and he connects the concept of dignity to spirituality. As examples of dialogue with patients, he suggests that clinicians ask, "Who else should we get involved at this point, to help support you through this difficult time?" --giving as an example, chaplaincy (--see Box 4 on p. 186).]

Chochinov, H. M. "**Dying, dignity, and new horizons in palliative end-of-life care.**" *CA: A Cancer Journal for Clinicians* 56, no. 2 (March-April 2006): 84-103. Quiz on pp. 104-105. [(Abstract:) Palliative care practitioners are now better able than ever before to ameliorate end-of-life symptom distress. What remains less developed, however, is the knowledge base and skill set necessary to recognize, assess, and compassionately address the psychosocial, existential, and spiritual aspects of the patient's dying experience. This review provides an overview of these areas, focusing primarily on empirical data that has examined these issues. A brief overview of psychiatric challenges in end-of-life care is complemented with a list of resources for readers wishing to explore this area more extensively. The experience of spiritual or existential suffering toward the end of life is explored, with an examination of the conceptual correlates of suffering. These correlates include: hopelessness, burden to others, loss of sense of dignity, and desire for death or loss of will to live. An empirically-derived model of dignity is described in some detail, with practical examples of diagnostic questions and therapeutic interventions to preserve dignity. Other interventions to reduce existential or spiritual suffering are described and evidence of their efficacy is presented. The author concludes that palliative care must continue to develop compassionate, individually tailored, and effective responses to the mounting vulnerability and increasingly difficult physical, psychosocial, and spiritual challenges facing persons nearing the end of life. (97 references)]

Chochinov, H. M. and Cann, B. J. "**Interventions to enhance the spiritual aspects of dying.**" *Journal of Palliative Medicine* 8, suppl. 1 (2005): S103-115. [(Abstract:) In recent years, medical and allied health publications have begun to address various topics on spirituality. Scholars have posited numerous definitions of spirituality and wrestled with the notion of spiritual pain and suffering. Researchers have examined the relationship between spirituality and health and explored, among other topics, patients' perceptions of their spiritual needs, particularly at the end of life. This paper summarizes salient evidence pertaining to spirituality, dying patients, their health care providers, and family or informal caregivers. We examine the challenging issue of how to define spirituality, and provide a brief overview of the state of evidence addressing interventions that may enhance or bolster spiritual aspects of dying. There are many pressing questions that need to be addressed within the context of spiritual issues and end-of-life care. Efforts to understand more fully the constructs of spiritual well-being, transcendence, hope, meaning, and dignity, and to correlate them with variables and outcomes such as quality of life, pain control, coping with loss, and acceptance are warranted. Researchers should also frame these issues from both faith-based and secular perspectives, differing professional viewpoints, and in diverse cultural settings. In

addition, longitudinal studies will enable patients' changing experiences and needs to be assessed over time. Research addressing spiritual dimensions of personhood offers an opportunity to expand the horizons of contemporary palliative care, thereby decreasing suffering and enhancing the quality of time remaining to those who are nearing death. (94 references)]

Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S. and Harlos, M. **"Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life."** *Journal of Clinical Oncology* 23, no. 24 (August 20, 2005): 5520-5525. [(Abstract:) PURPOSE: This study examined a novel intervention, dignity therapy, designed to address psychosocial and existential distress among terminally ill patients. Dignity therapy invites patients to discuss issues that matter most or that they would most want remembered. Sessions are transcribed and edited, with a returned final version that they can bequeath to a friend or family member. The objective of this study was to establish the feasibility of dignity therapy and determine its impact on various measures of psychosocial and existential distress. PATIENTS AND METHODS: Terminally ill inpatients and those receiving home-based palliative care services in Winnipeg, Canada, and Perth, Australia, were asked to complete pre- and post-intervention measures of sense of dignity, depression, suffering, and hopelessness; sense of purpose, sense of meaning, desire for death, will to live, and suicidality; and a post-intervention satisfaction survey. RESULTS: Ninety-one percent of participants reported being satisfied with dignity therapy; 76% reported a heightened sense of dignity; 68% reported an increased sense of purpose; 67% reported a heightened sense of meaning; 47% reported an increased will to live; and 81% reported that it had been or would be of help to their family. Post-intervention measures of suffering showed significant improvement ( $P = .023$ ) and reduced depressive symptoms ( $P = .05$ ). Finding dignity therapy helpful to their family correlated with life feeling more meaningful ( $r = 0.480$ ;  $P = .000$ ) and having a sense of purpose ( $r = 0.562$ ;  $P = .000$ ), accompanied by a lessened sense of suffering ( $r = 0.327$ ;  $P = .001$ ) and increased will to live ( $r = 0.387$ ;  $P = .000$ ). CONCLUSION: Dignity therapy shows promise as a novel therapeutic intervention for suffering and distress at the end of life.]

Chochinov, H. M., Kristjanson, L. J., Hack, T. F., Hassard, T., McClement, S. and Harlos, M. **"Dignity in the terminally ill: revisited."** *Journal of Palliative Medicine* 9, no. 3 (June 2006): 666-672. [(Abstract:) BACKGROUND: Several studies have been conducted examining the notion of dignity and how it is understood and experienced by people as they approach death. OBJECTIVE: The purpose of this study was to use a quantitative approach to validate the Dignity Model, originally based on qualitative data. DESIGN: Themes and subthemes from the Dignity Model were used to devise 22 items; patients were asked the extent to which they believed these specific issues were or could be related to their sense of dignity. RESULTS: Of 211 patients receiving palliative care, "not being treated with respect or understanding" (87.1%) and "feeling a burden to others" (87.1%) were the issues most identified as having an influence on their sense of dignity. All but 1 of the 22 items were endorsed by more than half of the patients; 16 items were endorsed by more than 70% of the patients. Demographic variables such as gender, age, education, and religious affiliation had an influence on what items patients ascribed to their sense of dignity. "Feeling life no longer had meaning or purpose" was the only variable to enter a logistic regression model predicting overall sense of dignity. CONCLUSIONS: This study provides further evidence supporting the validity of the Dignity Model. Items contained within this model provide a broad and inclusive range of issues and concerns that may influence a dying patient's sense of dignity. Sensitivity to these issues will draw care providers closer to being able to provide comprehensive, dignity conserving care.]