



September 2006 Article of the Month

This month's article selection is by Chaplain John Ehman,
University of Pennsylvania Medical Center-Penn Presbyterian, Philadelphia PA.

Leung, K.-K., Chiu, T.-Y. and Chen, C.-Y. "**The influence of awareness of terminal condition on spiritual well-being in terminal cancer patients.**" *Journal of Pain and Symptom Management* 31, no. 5 (May 2006): 449-456.

SUMMARY: While it is difficult to generalize research findings across different national/cultural contexts, this month's study from Taiwan may have value for chaplains in the US in two ways. First, it addresses a situation that is not uncommon: resistance to full disclosure of terminal illness to a patient--a situation in which chaplains sometimes become advocates for patients. Second, the study suggests a productive area for future research by chaplains.

The authors, all MDs, note that their study "may be the first report that empirically demonstrates the relationship between awareness of terminal illness and spiritual well-being at the end of life" [p. 453]. Their findings stand in opposition to beliefs that knowledge of terminal illness "might cause patients to lose hope and hasten their death" [p. 450] and compliment other research that indicates that attempts to protect patients from knowledge about a terminal condition may be fruitless [--see p. 450].

Participants were thirty-seven "consecutive eligible patients who were admitted and died in the hospices of three hospitals" [p. 452] in Taipei, Taiwan from January to July 2004. Data were gathered from "main family caregivers of the deceased patients" [p. 452]. During the process of admission to the study, "detailed and tactful interviews with patients and families" [p. 451] allowed for assessment of patients' awareness of terminal condition, acceptance of death, expectations of hospice treatment, and whether or not a patient had made a testament. The patients were mostly Buddhist men, whose wives subsequently completed a Spiritual Transcendence Measure (STM) developed for the study.

Central to this research is the Spiritual Transcendence Measure (STM), a 22-item instrument covering three domains of spirituality--Situational, Moral and Biographical, and Religious--based upon a conceptual model of spirituality by Allan Kellehear [--see Related Items of Interest, below]. The items of the STM are given in an Appendix on p. 456, and its Likert scoring is explained on p. 451. The authors chose to develop this instrument because they were dissatisfied with established measures like the Spiritual Well-Being Scale or the FACIT-Sp and wanted a measure that might be more in tune with Chinese culture [--see pp. 450-451]. Psychometric analysis of the STM is said to have shown "promising results in this study" [p. 453]. To this reader, the STM is not radically different from the older measures, though I was struck by the presence of two items specifically referring to "an afterlife," as that concept does not explicitly figure into the Spiritual Well-Being Scale or the FACIT-Sp. [For more on these latter two scales, see the [February 2004](#) and [March 2004](#) Articles-of-the-Month pages.]

Among the findings: "All patients in this study acknowledged their cancer diagnoses. However, 12 patients (32.4%) were unaware that they were terminally ill" [p. 452]. "Patients aware of their terminal condition had a higher proportion of making a dying will...and had greater acceptance of death...than those who were unaware of their terminal condition" [p. 452]. "Awareness of terminal illness, acceptance of death, and announcement of testament were highly associated with each other and were associated with spirituality" [p. 454]. "Patients who were aware of their terminal illness had a significantly higher score in the three dimensions of the STM and the STM as a whole than those who were unaware of their terminal illness" [p. 453].

The authors speculate in their discussion:

Why awareness of terminal illness affects spiritual well-being is a difficult question to answer. Faced with imminent death, people may redirect and reevaluate their lives and turn their attention from bodily needs to spiritual needs. ...Hope is an essential need for human beings. Understanding one's life expectancy may allow people to refocus their hope on "being" rather than "doing," to emphasize relationships with others and with God and to explore the belief regarding life after death. When patients begin to think about and bring up their spiritual issues, they may have the chance to explore and finally resolve them. Thus, awareness of terminal illness may become a turning point, which people set forth to deal with their spiritual needs and reach a better level of spiritual well-being. On the other hand, for patients whose lives have no pleasure, death becomes a release from suffering. Awareness of terminal illness becomes a comfort because people know that death is close at hand. [p. 254]

Such speculation is ventured with appropriate caution, and the authors provide good analysis of the study's limitations, including small sample size, reliance upon surrogates for the STM, and confounding factors related to truth-telling and spiritual well-being [--see p. 455]. Nevertheless, the study "point[s] out some important clinical implications and directions for future studies" [p. 455]. Chaplains might take from this a cue to look more closely at the relationship between patients' awareness of terminal illness and not only spiritual well-being but opportunities for pastoral care in general, since a patient's lack of awareness of his or her condition would logically seem to hamper both requests/referrals for a chaplain's involvement and constrain the chaplain's interventions upon involvement. Of course, in the US, the drive in recent years for patients' rights, the ascendancy of the ethical principle of autonomy, and requirements for informed consent for medical treatment all work to ensure proper disclosure to patients. Yet, there may still be delays in disclosure and tension between families and staff over the issue, such that patients may experience a *period* of avoidance or even lie-telling around medical diagnosis and prognosis, and the effects of that experience itself may be deleterious--another topic for research.

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

Students may want to discuss at the outset the trouble of generalizing a study's findings, especially across national/cultural lines, yet think how some aspects of culture that are dominant in one context may be more subtly present in other cultural contexts: for instance, the value of non-disclosure that is discussed broadly in our article in a Chinese cultural context may be manifest in American culture at the level of regional or particular family culture or the culture of a specific health care institution. The article will likely spark some recollections of requests not to tell patients about "bad news" and the awkwardness of visiting patients under such a "gag order." Discussion could also turn to what extenuating circumstances might actually justify non-disclosure, such as a patient's extreme psychological frailty, requests by a patient not to be informed, or the need to delay information until support systems are in place. For research-focused students, the article offers a good deal of material to consider, in terms of how certain patient characteristics relate to one another and to the domains of the Spiritual Transcendence Measure, but students who do not have experience with statistics should be advised not to become bogged down in that aspect of the authors' presentation. Students should note the mention of chaplains on pp. 451 and 455.

Related Items of Interest:

Fallowfield, L. J., Jenkins, V. A. and Beveridge, H. A. "**Truth may hurt but deceit hurts more: communication in palliative care.**" *Palliative Medicine* 16, no. 4 (July 2002): 297-303. [The authors, from the University of Sussex, England, argue from research, ethics, and practical experience to make a case against the censorship of information given to patients. The article does not discuss spirituality, and the British context may be one of greater medical paternalism than a US context, but the piece makes for interesting background reading about the dynamics of physician-patient communication around "bad news."]

Kellehear, A. "**Spirituality and palliative care: a model of needs.**" *Palliative Medicine* 14, no. 2 (March 2000): 149-155. [The author, a Professor of Palliative Care at La Trobe University in Melbourne, Australia, presents a theoretical model of spiritual needs based upon his review of palliative care literature. (This model is the foundation for the measure by Leung, et al. in this month's featured article.) Kellehear focuses on three "sources of transcendence, the building blocks of spiritual meaning" (p. 149, abstract): the Situational, the Moral and Biographical, and the Religious. Elements of Situational Needs are noted as Purpose, Hope, Meaning and Affirmation, Mutuality, Connectedness, and Social Presence. Elements of Moral and Biographical Needs are noted as Peace and Reconciliation, Reunion with Others, Prayer, Moral and Social Analysis, Forgiveness, and Closure. Elements of Religious Needs are noted as Religious Reconciliation, Divine Forgiveness and Support, Religious Rites/Sacraments, Visits by Clergy, Religious Literature, and Discussion about God, Eternal Life and Hope (--see pp. 150-153). He discusses implications for research and clinical practice.]

Krisman-Scott, M. A. "**An historical analysis of disclosure of terminal status.**" *Journal of Nursing Scholarship* 32, no. 1 (2000): 47-52. [The author, a nursing doctoral student at the time of publication, offers a broad historical overview of the topic, with emphasis on circumstances affecting American health care in the 1950s, 1960s, and 1970s. There is little analysis of the period from 1980 to the mid-1990s. She does note one nursing author from the 1950s (B. Arminger) who argued that patients should know the seriousness of conditions so that they might prepare spiritually for death. (Krisman-Scott has also written, "**Origins of hospice in the United States: the care of the dying, 1945-1975,**" in the October-December 2003 issue of the *Journal of Hospice and Palliative Nursing*, vol. 5, no. 4, pp. 205-212.)]

Kutner, J. S., Steiner, J. F., Corbett, K. K., Jahnigen, D. W. and Barton, P. L. "**Information needs in terminal illness.**" *Social Science and Medicine* 48, no. 10 (May 1999): 1341-1352. [This study of 22 terminally ill patients considers information needs about spiritual concerns as well as about such things as disclosure of "bad news," though there is no direct connection made between spirituality and medical disclosure issues. The study, however, illustrates well the inconsistency and ambivalence of patients confronted with grave illness: for example, while 100% of the patients said that they "want doctors to be honest," only 80.4% said they "want to know [the] expected course of [the] disease," and only 64.3% said that they wanted to know "if [they] will be in pain in [the] future" (--see table 2, p. 1346). This "conflict between wanting more information and not wanting bad news" (p. 1349) seems clearly pertinent to the study of medical disclosure in general.]

McClain, C. S., Rosenfeld, B. and Breitbart, W. "**Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients.**" *Lancet* 361, no. 9369 (May 10, 2003): 1603-1607. [This study of 160 patients with a life expectancy of less than three months used a variety of measures, including the FACIT-Sp. Spiritual well-being was significantly negatively correlated with hopelessness, suicidal ideation, and desire for hastened death. (The title of this article is incorrectly noted by Leung et al. in this month's featured study as "*The influence of spiritual well being....*")]

