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Spiritual Issues as an Essential Element of Quality Palliative Care: A Commentary

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"Last Hours of Life: Encouraging End-of-Life Conversations" by Stump, Klugman, and Thornton provides an excellent analysis of the critical domains of quality end-of-life care.[1] Their solid study demonstrates the evidence needed to ensure that all dimensions of patients' lives are included: the spiritual and psychosocial, as well as the physical. The Nevada Center for Ethics and Health Policy (NCEHP) should also be credited for its foresight and leadership in adopting the new worksheet for addressing important issues for end-of-life care.

Hospice and palliative care recognize the importance of the spiritual dimension in the care of dying patients. When Cicely Saunders started St. Christopher's Hospice in London, she listed one of the goals to be the relief of "total pain," including the physical, emotional, social, economic, and the spiritual.[2] The basic tenets of this field are rooted in patient-centered care: attention to all these dimensions of a patient — physical, emotional, social, and spiritual.

Spirituality, broadly defined as that which gives meaning and purpose to life, is often a central issue for patients at the end of life and for those dealing with chronic illness.[3] Every individual has to make a decision as to whether one's life has meaning and value.[4] As people face their dying, that search for meaning becomes more intense, thus their main task might be answering the fundamental question of what is their *ultimate* meaning and purpose in life. Throughout life, all people find meaningful activities and relationships. Impending death forces one to move deeper within, to a meaning that can withstand loss and even death. This is a profound journey that patients often describe as leading to indescribable joy and intensity, as they find a meaning that transcends the physical. Numerous surveys indicate that people turn to spiritual and/or religious beliefs in times of stress, serious illness, loss, and dying.[5] It is not uncommon for people to question their life choices and their relationships, including their relationship with God.

The spiritual issues that people face include hopelessness, despair, guilt, shame, anger, and abandonment by God or others. These issues can provoke deep suffering, which can result from people feeling alienated from themselves, others, God, or from their ultimate source of meaning. If these deep questions are not attended to, suffering may result, as people struggle with despair or hopelessness. Spirituality helps one to find meaning in the midst of suffering and to accept life's difficulties.

In more recent years, the National Consensus Project for Quality Palliative Care (NCP) identified spiritual care as one of eight domains in its report, *Clinical Practice Guidelines for Quality Palliative Care*.[6] The NCP recommendations for spiritual care emphasize regular and ongoing assessment of and response to

patients' spiritual and existential issues and concerns. The NCP emphasizes the use of a spiritual assessment to identify the religious or spiritual preferences, beliefs, rituals, and practices of patients and their family members. The *Clinical Practice Guidelines* also recognize the need for inclusion of pastoral care in the interdisciplinary care team. The *Clinical Practice Guidelines* have been adopted by the National Quality Forum (NQF), one of the leading national forces for quality in healthcare.

The American College of Physicians, in a consensus conference on physicians' role in end-of-life care, determined that physicians have an ethical obligation to attend to all dimensions of a seriously ill or dying patient — patients' psychosocial and spiritual suffering, as well as physical suffering.[7]

Addressing spirituality in healthcare is especially important when a patient is dealing with a serious illness. The *ICN Code of Ethics for Nurses* states, "The nurse promotes an environment in which the human rights, values, customs, and spiritual beliefs of the individual, family, and community are respected."[8] The "Code of Ethics of the National Association of Social Workers" declares, "social workers should obtain education about and seek to understand the nature of social diversity and oppression with respect to . . . religion.[9] Sulmasy has written of medicine as a moral enterprise, and that it is morally imperative that healthcare professionals attend to patients' spiritual needs and issues.[10]

Numerous studies report that spiritual issues are paramount in the care of seriously ill and dying patients. Spiritual and religious beliefs affect how people cope with serious illness and life stresses; spirituality and religion can improve coping,[11] improve quality of life,[12] will to live,[13] and provide social support.[14] Spirituality and religion have been associated with decreased depression in patients.[15] Spiritual beliefs affect healthcare decision making.[16]

Yet in spite of the history of the biopsychosocial-spiritual model of care in palliative care, professional ethical mandates to address spiritual concerns, and research supporting its importance, patients' spiritual needs often are not addressed. In a recent study, Balboni and colleagues reported that 75 percent of terminally ill cancer patients said that spiritual issues were not addressed by their healthcare professionals.[17]

This suggests that healthcare professionals and family members need practical tools to address the spiritual issues that patients and their family members face. The article by Stump and colleagues provides an excellent tool based on the biopsychosocial-spiritual model of care. It helps clinicians and patients identify the spiritual, physical, and psychosocial issues patients face at the end of life. This tool identifies critical questions that will enable patients and their family members to reflect on important questions related to dying. It helps healthcare professionals create an environment of trust and willingness and to hear from the patient or family whatever concerns they may have, including the spiritual and psychosocial ones.

The worksheet can be used as indicated in the article, in end-of-life situations. But it also has broader applications. It can be used in clinical education programs with healthcare professional students to explore issues around death and dying. It can be used across all phases of life, as patients and clinicians discuss advance care planning in the clinical setting. It can be used in any situation in which one begins to approach the critical questions that will ultimately face all of us: Who am I? or Who will I be in the face of my active dying? What is the ultimate meaning and purpose of my life?

NOTES

1. B. Stump, C.M. Klugman, and B. Thornton, "Last Hours of Life: Encouraging End-of-Life Conversations," in this issue of *The Journal of Clinical Ethics.*

2. F.S. Wald, "In Search of the Spiritual Component of Hospice Care," in *In Search of the Spiritual Component of Hospice Care,* ed. F.S. Wald (New Haven, Conn.: Yale University Press, 1986).

3. C.M. Puchalski, E. Dorff, and Y. Hendi, "Spirituality, religion, and healing in palliative Care," *Clinics in Geriatric Medicine* 20, no. 4 (November 2004): 689-714; A.B. Astrow, C.M. Puchalski, and D.P. Sulmasy, "Religion, spirituality, and health care: Social, ethical, and practical considerations," *American Journal of Medicine* 110, no. 4 (March 2001): 283-7; D.P. Sulmasy, "A Biopsychosocial-Spiritual Model for the Care of Patients at the End of Life," *Gerontologist* 42, spec. no. 3 (October 2002): 24-33.

4. D.P. Sulmasy, "Is medicine a spiritual practice?" *Academic Medicine* 74, no. 9 (September 1999): 1002-5.

5. C.M. Puchalski, "Spirituality and the Care of Patients at the End-of-Life: An Essential Component of Care," *Omega* 56, no. 1 (2007-2008): 34-46.

6. National Consensus Project for Quality Palliative Care, *Clinical Practice Guidelines for Quality Palliative Care*, 2004, *www.nationalconsensus project.org/Guideline.pdf*, accessed 29 June 2008.

7. B. Lo, T. Quill, and J. Tulsky, "Discussing Palliative Care with Patients. ACP-ASIM End-of-Life Care Consensus Panel," *Annals of Internal Medicine* 130 (1999): 744-9.

8. International Council of Nurses, *ICN Code of Ethics for Nurses* (Geneva: ICN, 2006), 2, *www.icn.ch/icncode.pdf*, accessed 7 July 2008.

9. "Code of Ethics of the National Association of Social Workers, Approved by the 1996 NASW Delegate Assembly and revised by the 1999 NASW Delegate Assembly," *http://www.socialworkers .org/pubs/Code/code.asp*, accessed 7 July 2008.

10. Sulmasy, "Is medicine a spiritual practice?" see note 4 above.

11. H.G. Koenig, M.E. McCullough, and D.B. Larson, *Handbook of Religion and Health* (New York: Oxford University Press, 2001).

12. S.R. Cohen et al., "Existential Well-being Is an Important Determinant of Quality of Life, Evidence from the McGill Quality of Life Questionnaire," *Cancer* 77, no. 3 (1 February 1996): 576-86.

13. S. Cotton et al., "Spirituality and Religion in Patients with HIV/AIDS," *Journal of General Internal Medicine* 21, supp. 5 (December 2006): S5-13.

14. S.C. Burgener, "Predicting Quality of Life in Caregivers of Alzheimer's Patients: The Role of Support From and Involvement With the Religious Community," *Journal of Pastoral Care* 53, no. 4 (Winter 1999): 443-6.

15. M. Yi et al., "Religion, Spirituality and Depressive Symptoms in Patients with HIV/AIDS," *Journal of General Internal Medicine* 21, supp. 5 (December 2006): S21-7.

16. G.A. Silvestri et al., "Importance of Faith on Medical Decisions Regarding Cancer Care," *Journal of Clinical Oncology* 21, no. 7 (April 2003): 1379-82.

17. T.A. Balboni et al., "Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life," *Journal of Clinical Oncology* 25, no. 5 (2007): 555-60.