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Placing Religion and Spirituality in End-of-Life Care

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IN 1995, THE SUPPORT (STUDY TO UNDERSTAND PROGNOSIS and Preferences for Outcomes and Risks of Treatment) trial stimulated a reexamination of systems of care for seriously ill and dying patients.¹ This study has accelerated efforts to improve end-of-life care and has indirectly promoted a rapprochement among religion, spirituality, medicine, and health care.² The goal of a quality comfortable death is achieved by meeting a patient's physical needs and by attending to the social, psychological, and the now recognized spiritual and religious dimensions of care.^{3,4} This perspective is highlighted in a recent consensus statement that includes the assessment and support of spiritual and religious well-being and management of spiritual and religious problems as core principles of professional practice and care at the end of life.⁵ Yet multiple ethical and pragmatic issues arise. For example, should physicians identify patients' spiritual and religious needs and intervene in clinical settings? The roles and responsibilities of patients and physicians in this scenario are unclear. An understanding of religion and spirituality within the context of end-of-life care, quality of life, and patient-clinician interactions may illuminate the problems and potentialities for both patients and clinicians.

Religion: The Provision of Belief and the Establishment of an Ethic

The distinction between religion and spirituality is an important and nuanced one. From its Latin roots (*religio*), religion has been associated with various connotations: the totality of belief systems, an inner piety or disposition, an abstract system of ideas, and ritual practices.⁶ In end-of-life care, religion and religious traditions serve 2 primary functions: the provision of a set of core beliefs about life events and the establishment of an ethical foundation for clinical decision making.⁷ Religious doctrine and belief systems provide a framework for understanding the human experience of death and dying for patients, family members, and health care professionals. Intuitively, strong religious beliefs, whether expressed or privately held, should be associated with a decreased fear of death and greater acceptance of death. However, research that has examined the in-

teraction between religious belief and attitudes toward death has produced controversial results that generally do not support this assumption.⁸

In addition, religious traditions include substantial normative and ethical issues in end-of-life care.⁷ Ethics in this context spans a wide range of human interaction from interpersonal to organizational levels and represents the moral response to approaching and encountering death. Religion-based ethics provides a point of reference for clinical decision making and many religious groups, such as the National Conference of Catholic Bishops,⁹ the Unitarian Universalist General Assembly,¹⁰ and the Conservative Movement's Committee on Jewish Law and Standards,¹¹ actively participate in public discourse about issues that accompany the end of life (eg, palliative care, withdrawal of advanced life support, advance care planning). Although these sources provide an ethical framework for decisions at the end of life,¹² religion-based ethics can both facilitate and impede clinical decision making,¹³ which reflects a dynamic interplay among patients, family members, clinicians, and institutions.

The issues of physician-assisted suicide (PAS) and euthanasia exemplify the complex interaction between religious belief and ethical decision making in end-of-life care. Recent studies have found an inverse association between measures of religiousness and attitudes toward PAS. A survey of physicians, nurses, and social workers in New York City found that respondents who had lower levels of religious belief were more willing to endorse assisted suicide than those who reported higher levels of belief.¹⁴ This finding is consistent with a national study by Emanuel et al¹⁵ who found that oncologists who report high or moderate levels of religious belief were less likely to perform euthanasia or PAS than those who reported no religious belief. In a national survey of US physicians representing specialties most likely to receive patient requests for assistance with suicide or euthanasia, Meier et al¹⁶ reported that physicians who have no religious affiliation were more likely to be willing to provide assistance and to have complied with a patient request for PAS than those with a religious affiliation.

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These findings parallel those from patient populations as well. A study of patients with amyotrophic lateral sclerosis living in Oregon and Washington found that respondents who scored higher on a scale measuring the importance of religion were less likely to consider assisted suicide than those with lower scores.¹⁷ In 2 studies of older adults, the degree of self-reported strength of religious beliefs or role of religion in life was inversely proportional with more permissive attitudes toward assisted suicide.^{18,19} For both patients and physicians, these studies suggest that religious belief may have a significant effect on ethical decision making at the end of life.

Spirituality: Resources for Personal Meaning

Spirituality may or may not be linked to religious beliefs, religious practices, or communities that support those practices and beliefs.²⁰ Terminally ill patients acknowledge a greater spiritual perspective and orientation than both nonterminally ill hospitalized patients and healthy patients.²¹ Although there are multiple interpretations of spirituality within health care settings,²² constructs of meaning or a sense of life's purpose have been suggested as primary components.²³ For example, in women with advanced breast cancer, maintaining a purpose or meaning in life has been identified as an important aspect of self-transcendence and spiritual well-being.^{24,25} The coping literature delineates 2 forms of meaning: implicit meaning and found meaning.²⁶ Implicit meaning is an appraisal process that involves the gathering and processing of medical information.²⁷ Found meaning, or meaningfulness, interprets and places this information into a larger life context.²⁶ Antonovsky²⁸ describes this generally positive, pervasive way of seeing the world, and one's life in it, as a "sense of coherence," lending comprehensibility and manageability.

Psychological states and quality-of-life outcomes have been the primary end points in end-of-life care studies that have incorporated a measure of spirituality. For example, among oncology patients, modest correlations have been found between spirituality and lower levels of anxiety and psychosocial distress.^{29,30} Additional studies suggest that spirituality is also positively associated with subjective well-being²¹ and quality of life to the same degree as physical well-being.³¹

Quality of Life

In clinical and research settings, quality-of-life assessment examines the social, physical, and psychological influences on patient illness, health, and well-being.³² Measures of religiousness and spirituality that are specific to end-of-life care vary in their content, validity, and reliability, which reflect the developmental state of work in this area. The McGill Quality of Life Questionnaire³³ incorporates items to assess achievement of life goals and personal meaning, while the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being³¹ scale contains questions that mea-

sure the comfort and strength derived from religious faith, in addition to a sense of meaning, purpose, and peace in life. The Systems of Belief Inventory,³⁴ which was designed for use in quality-of-life and psychosocial research examining illness adjustment, measures religious and spiritual beliefs and practices and the social support that accompanies those beliefs and practices.

Religion and spirituality potentially can mediate quality of life by enhancing patient subjective well-being through social support and stress and coping strategies. Theoretically, religious and spiritual beliefs may enhance subjective well-being in 4 ways: promoting a salubrious personal lifestyle that is congruent with religious or personal faith traditions, providing systems of meaning and existential coherence, establishing personal relationships with a divine other, and ensuring social support and integration within a community.³⁵ Social support has been suggested as an intervening factor between quality of life and religion and spirituality. The positive impact of social support and support groups on survival in cancer patients generated considerable interest in the early 1990s,³⁶ although follow-up studies have failed to replicate earlier findings.³⁷ Religious and spiritual beliefs have been found to be beneficial when examined within theoretical models of stress and coping.³⁸ Research on religious approaches to coping and problem solving have been predictive of successful psychological adjustment to stressful life events.³⁹ For example, Jenkins and Pargament⁴⁰ report that cancer patients who attribute more control over their illness to God have higher self-esteem and are more adjusted to their disease state than those who do not attribute such control to God.

Patient-Clinician Interactions and Interventions

Assessment of quality of life raises some practical and ethical issues regarding the clinician's role in spiritual and religious support during end-of-life care. How do physicians and nurses frame religious and spiritual concerns within health care settings? Are religious and spiritual concerns subsumed within social and psychological constructs and domains that comprise an individual's experience of illness and disease, or are spirituality and religion conceptualized and viewed a priori? This tension is highlighted by recommendations and initiatives that incorporate religion and spirituality in plans to improve care at the end of life. For example, assessment guidelines for palliative care plans developed by the Institute of Medicine embed spiritual assessment within measures of emotional status.⁴¹ However, a report from the Commonwealth-Cummings project lists spiritual and existential beliefs as an independent modifiable dimension of the patient's dying experience.⁴

The inconsistent orientation and lack of conceptual clarity that accompany religion and spirituality raise several secondary questions relative to the operationalization of any guideline or recommendation. Who is responsible for assessing and meeting the spiritual and religious needs of

dying patients: physicians, nurses, social workers, psychologists, or clergy and health care chaplains? Some have advocated that physicians or other members of the health care team should address these issues.⁴² Yet within the patient-physician relationship, physicians wield a power that is largely positive and salutary, and this power may result in a loss of patient autonomy if left unchecked or unguarded.⁴³ In the development of treatment goals and care plans, patient autonomy can be threatened when physicians' religious convictions are dissonant with those of patients and family members. For example, studies that measured physician religiousness and PAS support the assumption that physicians' religious belief may influence the patient-physician relationship. In light of these concerns, data from a US national survey suggest that clergy and professional pastoral care providers assume a primary role for religious and spiritual concerns in clinical settings.⁴⁴ In this survey, more than 80% of family physicians reported that they refer to these clergy and pastoral care providers in conditions associated with end-of-life care. However, if quality of life is enhanced by the search for personal meaning, should physicians and other health care professionals also incorporate these aspects in care? Would physicians' approaches differ from those of professional pastoral care providers tied to religious or faith traditions? These issues are fertile ground for future research.

Future Directions: Hospice as a Sentinel Model

The hospice movement provides a case study to examine the development of religion and spirituality within end-of-life care. The foundation of the modern hospice movement was grounded in a Western Christian religious tradition.⁴⁵ This faith tradition served a primary function for hospice by providing an ethical foundation and a set of core beliefs, initially for a small committed group of people in the United Kingdom in the 1960s. Saunders, who pioneered the hospice movement, provided much of the philosophical framework that still underlies contemporary hospice,⁴⁶ and the mission statement for one of the original hospices, St Christopher's, remains rooted within this religious tradition.⁴⁵ But as the hospice movement grew and encountered patients and health care professionals who often did not share this tradition, hospice had to accommodate and modify its mission or risk alienating a constituency that it was founded to serve. Today hospice maintains a global approach to patient care with an emphasis on relieving suffering, but the religious basis and foundation for this care are conspicuously absent.

Religious traditions provide a framework for both individual and organizational ethics, and it is uncertain how loosening the ties of hospice to a specific religious tradition may affect the hospice ethos. For example, although the place of euthanasia and PAS is often minimized and discouraged in hospice settings,⁴⁶ recent research suggests that these organizational values may not be pervasive. In one survey of

US oncologists, approximately 40% of patients were receiving hospice care at the time of euthanasia or PAS,¹⁵ while an additional study found that 32% of patients in Oregon enrolled in a hospice program requested a prescription for lethal medications.⁴⁷ Although these studies do not imply that hospice care has a waning emphasis on religious and spiritual concerns, it is unclear whether these findings represent a limitation of hospice care in individual cases, a compassionate response to the control of pain and suffering in these settings, or the fact that most hospice care is only one, albeit important, component of the patient's life and decision-making contribution.

Hospice considers the religious or spiritual dimension of the person as independent and not subsumed within social or psychological domains. The World Health Organization also holds a similar perspective and defines palliative care as

the active total care of patients whose disease is not responsive to curative treatment . . . [when] control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount.⁴⁸

The understanding of spirituality has also evolved. For example, hospice's original religious definition of spirituality as a relationship with God or a Divine Other has been replaced by a definition of spirituality as the personal and psychological search for meaning.⁴⁵ This trend is part of a larger cultural movement in the United States in which there is a transition from a traditional membership in a faith community to a spirituality of seeking.⁴⁹ The increase in quality-of-life research that includes measures of spirituality and the spiritual resources in hospice care are manifestations of the widespread acceptance of a spirituality that is uprooted from its religious sources. The distancing of religious beliefs from spirituality has facilitated a greater and necessary acceptance of hospice into a multicultural world, one in which hospice workers may move about among many different faith traditions.

Yet religion and faith traditions still occupy a substantial place in end-of-life care. From a social constructionist perspective, social determinants such as social support, education, gender, and religion are primary elements that facilitate the interpretation and understanding of death and dying.⁵⁰ In this context, religious and faith traditions may be part of the scaffolding in the construction of meaning as death approaches. Spirituality may be viewed as the actions and interactions of an embodied human actor who is facing death and creating a personally meaningful social world, a constructed world that can be either a resource or an encumbrance.⁵⁰ For hospice and palliative care this has several implications: a richer appreciation of the social and demographic determinants of a quality care at the end of life, a greater understanding of the psychological and theological processes involved in "meaning making," and an emphasis on assessment strategies and interventions that are inclusive of these factors.

When viewed from either a constructionist or phenomenological perspective, the ties that bind hospice to palliative care in the assessment and management of spiritual concerns are best understood by examining the locus of care at the end of life. Multiple connotations of hospice exist, yet many associate this term with a physical place of respite and care. In the evolution of end-of-life care and the emergence of the disciplines of palliative care, there has been a shift in the common understanding of hospice from an institution that provides care to a philosophy that embodies the active, total care of the individual.⁵¹ Hospice and palliative care have negotiated much of the difficult terrain that accompanies religion and spirituality and medicine, and they have done so by moving the locus of care out of biomedical institutions back into the community. By offering a health care delivery model that incorporates a community-based approach while emphasizing the uniqueness of the individual, regardless of the importance of religion or spirituality in the individual's life, hospice and palliative care provide a structure for and facilitate the processes that are involved in this most basic of human experiences, that of dying.

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REFERENCES

- SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT). *JAMA*. 1995;274:1591-1598.
- Daaleman TP. A cartography of spirituality in end-of-life care. *Bioethics Forum*. 1997;13:49-52.
- Byock R. *Dying Well: The Prospect for Growth at the End of Life*. New York, NY: Riverhead; 1997.
- Emanuel EJ, Emanuel LL. The promise of a good death. *Lancet*. 1998;351 (suppl 2):S21-S29.
- Cassel CK, Foley KM. *Principles for Care of Patients at the End of Life: An Emerging Consensus Among the Specialties of Medicine*. New York, NY: Milbank Memorial Fund; 1999.
- Wulff DM. *Psychology of Religion: Classic and Contemporary*. New York, NY: John Wiley & Sons; 1997.
- O'Connell LJ. Religious dimensions of dying and death. *West J Med*. 1995; 163:231-235.
- Neimeyer RA, ed. *Death Anxiety Handbook, Research, Instrumentation, and Application*. Washington, DC: Taylor & Francis; 1994.
- National Conference of Catholic Bishops. *Ethical and Religious Directives for Catholic Health Care Services*. Washington, DC: United States Catholic Conference; 1994.
- General Assembly of Unitarian Universalists. *The Right to Die with Dignity: Proceedings of General Assembly*. Boston, Mass: Unitarian Universalist Association; 1988.
- Dorff E. A Jewish approach to end-stage medical care. *Conservative Judaism*. 1991;43:3-51.
- Dubose ER. *Physician Assisted Suicide, Religious and Public Policy Perspectives*. Chicago, Ill: The Park Ridge Center; 1999.
- Post SG. Medical futility and the free exercise of religion. *J Law Med Ethics*. 1995;23:20-26.
- Portenoy RK, Coyle N, Kash KM, et al. Determinants of the willingness to endorse assisted suicide, a survey of physicians, nurses, and social workers. *Psychosomatics*. 1997;38:277-287.
- Emanuel EJ, Daniels ER, Fairclough DL, Clarridge BR. The practice of euthanasia and physician-assisted suicide in the United States. *JAMA*. 1998;280:507-513.
- Meier DE, Emmons CA, Wallenstein S, et al. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med*. 1998;338: 967-973.
- Ganzini L, Johnston WS, McFarland BH, Tolle SW, Lee MA. Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. *N Engl J Med*. 1998;339:967-973.
- Seidlitz L, Duberstein PR, Cox C, Conwell Y. Attitudes of older people toward suicide and assisted suicide: an analysis of Gallup Poll findings. *J Am Geriatr Soc*. 1995;43:993-998.
- Sullivan M, Ormel J, Kempen GJ, Tymstra T. Beliefs concerning death, dying, and hastening death among older, functionally impaired Dutch adults: a one-year longitudinal study. *J Am Geriatr Soc*. 1998;46:1251-1257.
- Van Ness PH. *Spirituality and the Secular Quest*. New York, NY: Continuum; 1996.
- Reed PG. Spirituality and well-being in terminally ill hospitalized adults. *Res Nurs Health*. 1987;10:335-344.
- Larson DB, Swyers JP, McCullough ME, eds. *Scientific research on spirituality and health: a consensus report*. Rockville, Md: National Institute of Healthcare Research; 1998.
- Fitchett G, Handzo G. Spiritual assessment, screening, and intervention. In: Holland JC, ed. *Psycho-oncology*. New York, NY: Oxford University Press; 1998: 790-808.
- Coward DD. The lived experience of self-transcendence in women with advanced breast cancer. *Nurs Sci Q*. 1989;3:162-169.
- Hassey Dow K, Ferrell BR, Leigh S, et al. An evaluation of the QOL among long-term survivors of breast cancer. *Breast Cancer Res Treatment*. 1996;39:261-273.
- Thompson SC, Janigian AS. Life schemes: a framework for understanding the search for meaning. *J Soc Clin Psychol*. 1988;7:260-280.
- Lazarus RS, Folkman S. *Stress, Appraisal, and Coping*. New York, NY: Springer; 1984.
- Antonovsky A. *Unraveling the Mystery of Health: How People Manage Stress and Stay Well*. San Francisco, Calif: Jossey-Bass; 1987.
- Kaczorowski JM. Spiritual well-being and anxiety in adults diagnosed with cancer. *Hospice J*. 1989;5:105-116.
- Smith ED, Stefanek ME, Joseph MV, et al. Spiritual awareness, personal perspective on death, and psychosocial distress among cancer patients: an initial investigation. *J Psychosoc Oncol*. 1993;11:89-103.
- Brady MJ, Peterman AH, Fitchett G, Mo M, Cella D. A case for including spirituality in quality of life measurement in oncology. *Psychooncology*. 1999;8:417-428.
- Testa MA, Simonson DC. Assessment of quality of life outcomes. *N Engl J Med*. 1996;334:835-840.
- Cohen SR, Mount BM, Tomas J, Mount L. Existential well-being is an important determinant of quality of life: evidence from the McGill Quality of Life Questionnaire. *Cancer*. 1996;77:576-586.
- Holland JC, Kash KM, Passik S, et al. A brief spiritual beliefs inventory for use in quality of life research in life-threatening illness. *Psychooncology*. 1998;7:460-469.
- Ellison CG. Religious involvement and subjective well-being. *J Health Soc Behav*. 1991;32:80-99.
- Spiegel D, Bloom JR, Kraemer HC, Gotthel E. Effects of psychosocial treatment on survival of patients with metastatic breast cancer. *Lancet*. 1989;2:888-891.
- Cunningham AJ, Edmonds CV, Jenkins GP, et al. A randomized controlled trial of the effects of group psychological therapy on survival in women with metastatic breast cancer. *Psychooncology*. 1998;7:508-517.
- Krause N, Tan TV. Stress and religious involvement among older blacks. *J Gerontol*. 1989;44:S4-S13.
- Pargament KI. *The Psychology of Religion and Coping, Theory, Research, and Practice*. New York, NY: Guilford Press; 1997.
- Jenkins RA, Pargament KI. Cognitive appraisals in cancer patients. *Soc Sci Med*. 1988;26:625-633.
- Institute of Medicine. *Approaching Death: Improving Care at the End-of-Life*. Washington, DC: National Academy Press; 1997.
- Lo B, Quill T, Tulsky J, for the ACP-ASIM End-of-Life Care Consensus Panel. Discussing palliative care with patients. *Ann Intern Med*. 1999;130:744-749.
- Brody H. *The Healer's Power*. New Haven, Conn: Yale University Press; 1992.
- Daaleman TP, Frey B. Prevalence and patterns of physician referral to clergy and pastoral care providers. *Arch Fam Med*. 1998;7:548-553.
- Bradshaw A. The spiritual dimension of hospice: the secularization of an ideal. *Soc Sci Med*. 1996;43:409-419.
- Mathew LM, Scully JH. Hospice care. *Clin Geriatr Med*. 1986;2:617-634.
- Ganzini L, Nelson HD, Schmidt TA, et al. Physicians experiences with the Oregon Death with Dignity Act. *N Engl J Med*. 2000;342:557-563.
- World Health Organization. *Cancer Pain Relief and Palliative Care*. Geneva, Switzerland: World Health Organization; 1990. Technical Report Series 804.
- Wuthnow R. *After Heaven: Spirituality in America Since the 1950's*. Berkeley: University of California Press; 1998.
- Seale C. *Constructing Death, the Sociology of Dying and Bereavement*. Cambridge, England: Cambridge University Press; 1998.
- Doyle D, Hanks G, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. Oxford, England: Oxford University Press; 1999.