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# A Cartography of Spirituality in End-of-Life Care

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*Deficiencies in the care of the seriously ill and dying persons in the United States are challenging the traditional dichotomy between body and spirit as we reexamine the interplay between medicine and spirituality. A cartography of spirituality in end-of-life care is needed in order to analyze this interplay. A three-pronged topology is suggested: quality of life assessment, health care delivery, and patient-physician interaction.*

American medicine was awakened to reexamine the way it cares for dying patients by *SUPPORT — The Study to Understand Prognoses and Preferences for Outcome and Treatments* (The SUPPORT Principal Investigators 1995). Fallout from this study has accelerated interest and concern in improving care and has indirectly promoted a rapprochement among the realms of spirituality, health care, and medicine. This territory, encompassing the mystical and the medical, had been well traveled by patients and providers throughout antiquity and the Middle Ages. In recent centuries, however, its many paths have blended into two: the biomedical, and the spiritual or religious.

Deficiencies in care of the seriously ill and dying in the United States are provoking challenges to this dichotomy and causing us to reexamine the interplay of spirituality and medicine. We are returning to terrain that has been trodden but uncharted. Studies involving end-of-life care are largely silent about spiritual themes and perspectives that surround this basic human experience. One reason may be that we lack a conceptual framework and methodology by which spirituality can be examined in a clinical context. Another may be the near-exclusive appropriation of this care to clergy or pastoral care, traditional providers in this area.

A cartography of spirituality in end-of-life care is now essential to help us navigate the issues, problems, and potentialities of this journey. The process involved requires a circumspection that is

multidisciplinary, inclusive, and rigorous. Pastoral theology, epidemiology, medical sociology and anthropology, and biomedical ethics are the compass and surveyor's tripod for mapping this journey. A preliminary sketch suggests a topology consisting of three domains: quality-of-life assessment, health care delivery, and patient-physician interaction.

## **Fraternal Twins: Spirituality and Religion**

Before discussing a cartography of spirituality in end-of-life care, we should clarify the distinction between spirituality and religion. Spirituality, and its comfortable locus within the contemporary American psyche, has reemerged and developed within the last century. The word spirituality is derived from the Latin *spiritus*, which means breath, to breathe or blow. *Spiritualitas*, found in the fifth century, had a biblical meaning of a "spiritual person," one whose life is ordered or influenced by the Spirit of God. Despite such early and pervasive roots, spirituality was not routinely found in literary tracts in the eighteenth and nineteenth centuries, due to Voltaire and other contemporary writers who used the word disparagingly. In the early twentieth century the term "spirituality" resurfaced among French Catholic writers, and was used in its original religious or devotional sense (Wulff 1997).

Currently the term has several disparate meanings. Yet, there appears to be some commonality between various faith traditions and sociological and psychological perspectives. Spirituality is the animating manifestation of our human response

to others, to our inner selves, and to the transcendent (God) (Nouwen 1986). This movement acknowledges a universal and perpetual human need for community, love, and transcendence or meaning (Daaleman 1995).

Spirituality's misunderstood sibling, religion, derives from the Latin *religio*, "to revere the gods." The Greek translation, instead, is to heed or to have a care. This second usage acknowledges a super-human power, one that requires human response in order to avoid undesired consequences. The feeling of awe one gets in observing such power also is connoted. From these roots, religion has been placed in various contexts: the totality of a belief system; an inner piety or disposition; an abstract system of ideas; and as ritual practices (Wulff 1997).

Distinctions between religion and spirituality are important and nuanced. Today, most Americans readily acknowledge that they are spiritual, but not religious (Gallup 1997). There also is widespread interest in "new spirituality," a term arising from several influences in the last twenty-five years. Various social movements in the 1960s fostered exploration of and familiarity with different philosophical, religious, and spiritual traditions. These influences provided a metaphorical understanding of life as a journey or a quest, which had as its ideal end point a new outlook, perspective, or a higher state of awareness.

Today's economic and business management perspective has grounded much of the collective social and cultural consciousness. One result is the intrusion of organizational behavior models into noneconomic realms. This orientation emphasizes "self actualization," and promotes a growth and development perspective. Our familiarity with the theoretical and practical applications of "self-actualization" validates many of the practices and processes found in most spiritual traditions. Finally, the declining influence of institutional churches has loosened our traditional ties to religion and spirituality. As a result, the "new spirituality" is marked by frequent absences of a transcendent object (for example, God) outside of self. Life is viewed not in relation

to a divine force, but in reference to the possibilities of the human spirit (Wulff 1997).

### Quality-of-Life Assessment

Much current discussion about end-of-life care centers around issues related to quality of life. In both clinical and research settings, quality-of-life assessments examine social, psychological, and physical influences on a patient's illness, health, and well-being. Spirituality spans the social and psychological domains and can be viewed within the context of three areas: subjective well-being, social support, and stress and coping strategies.

Subjective well-being seeks to identify how patients perceive their illness and how this understanding impacts quality of life. Strong religious and spiritual beliefs exert a positive and substantial influence on subjective well-being in various populations. Theoretically these beliefs enhance well-being in four ways: by providing systems of meaning and existential coherence; by promoting specific patterns of religious organization and personal life-style; through establishing personal relationships with a divine other; and by ensuring social integration and support (Ellison 1991).

Social support impacts quality of life by providing coping strategies. Depression, anxiety, and emotional distress are common among those facing serious illness. Belief systems can assist with this care, independent of social support, as adaptations or modulators of stress. Spiritual and religious beliefs have been found to be beneficial when examined within theoretical models of stress and coping (suppressor, distress-deterrent, moderator, or preventer) (Kraus and Tran 1989). However, what remains unclear is the mechanism by which spirituality exerts its influence.

Belief systems often are expressed directly through private and institutional practices and behaviors. Prayer and meditation remain the predominant forms of spiritual and religious behavior found in end-of-life care. Salutory effects of these and other practices traditionally are accepted and encouraged by caretakers. Anecdotal accounts of reduced blood pressure and heart rate and enhanced immune responses have been sub-

stantiated in recent years through clinical research, which has identified neuroimmunologic and cardiovascular mechanisms involved. To some, these observations confirm and reinforce a mind-body-spirit connection. To others, such findings and interpretations are dismissed as placebo effects.

### **Health Care Delivery**

Social support may be the major reason why spirituality has a positive impact on well-being. The web of personal relationships that spirituality and religion provide can have beneficial effects on subjective well-being. The key role that relationship and social support play is gaining increased visibility in care of the seriously ill and dying.

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One reason may be that hospitals, medical centers, and other traditional biomedical institutions are no longer the exclusive sites of care. In addition, the services of physicians and other traditional member of health care delivery systems today are augmented by teams of both lay and professional caregivers. But despite the increased prevalence and acceptance of these changes, there still is an assumption that care of the seriously ill and dying should be delivered exclusively in medical centers and hospitals.

The hospice movement continuously challenges this perception. It offers a health care delivery model that emphasizes the uniqueness of the individual, while incorporating a collaborative, community-based approach. In doing so, it reframes this most basic of human experiences

into community. The concept of community as a healing entity is a recent development, one with roots in several spiritual traditions. Community, in this sense, is the network of relationships that provides a matrix of meaning, in addition to providing social support.

### **Patient-Physician Interaction**

Whether through a neurochemical response, social support, or placebo, what is undeniable is the power that spiritual and religious belief systems hold for both practitioner and patient. Three elements constitute the power in this clinical context: the belief systems of the patient; the belief systems of the physician or caregiver; and the relationship between the two parties (Benson 1996). The knowledge base, skills, and values that are key elements of relationship-centered or patient-centered care (self-awareness, patient experience of health and illness, developing and maintaining caring relationships, and effective communication) reinforce the importance of belief systems (Inui 1996). Although many studies have examined the patient-physician relationships in end-of-life care, little research has focused on belief systems of the patient.

Patients facing death often fear pain and loneliness in their suffering, loss of control, and uncertainty about what lies ahead. Before assisting patients on this journey, physicians and caretakers need to reflect and appraise their own belief systems.

Insight and self-awareness often are not viewed as essential elements in physician-patient relationships, but they are, nonetheless, the cornerstone upon which other care-giving skills are built. In order to understand a patient's sense of meaning regarding health, illness, and death, clinicians need to be attentive to, and cognizant of, their own fears, yearnings, and desires.

Physicians and caregivers who address the fears and needs of the seriously ill and dying often find themselves assuming fluid and varied roles. In the patient-physician relationship, physicians possess a power that is positive and salutary, but which can be harmful if unguarded or

unchecked. Clinicians need to be prudent when inquiring about a patient's belief system or when recommending spiritual interventions, since the physician's beliefs can influence this interaction. While recent survey data reveal that most Americans are searching for meaning in their lives and feel a hunger to experience God, a growing number of the "unchurched" also do not know what they believe or why (Gallup 1997).

In a social climate lacking religious and spiritual discernment, there is a need for clear understanding of the limits of spirituality and medicine. Medicine has always sought to cure, and when cure is not possible, to provide care in order to ease pain and suffering. Religion and spirituality promote union with God or the transcendent. While these distinctions are critical, they are becoming increasingly blurred with increased impetus toward wellness, healing, and wholeness. In end-of-life care, medicine and health care cannot provide meaning or an understanding of the human context for this experience. For most, spirituality, religion, or philosophy can provide these sources of meaning. Clinicians who incorporate religious or spiritual modalities into care of the dying must do so judiciously and guard against viewing such interventions simply as additional therapies in their medical armamentarium.

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