# Religion, Spirituality, and Existentialism Near the End of Life

## Implications for Assessment and Application

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*Persons facing death due to terminal illness experience diverse physical, emotional, and relationship challenges. Dying persons have more than just physical needs, and spiritual issues may feature prominently as sources of intense struggle and comfort as people prepare to die. The spiritual health of the dying may be as important as their biological condition when facing death. Nevertheless, the present health care environment, with its emphasis on diagnostics and curative treatment, may allocate minimal attention and resources to the spiritual needs of the dying and their families. The neglect of spiritual issues may contribute to emotional, cognitive, and physical difficulties experienced at the end of life. Therefore, recognizing spirituality within the biomedical context of dying is essential. This requires an appreciation for the multifaceted nature of spirituality, coupled with an openness to individual theology, and an ability to integrate the spiritual dimension within a "bio-psychosocial" framework of assessment.*

**Death is an ostensibly biomedical phenomenon** (Cobb, 2001; Nicassio & Smith, 1995; Steinhauser, Clipp, et al., 2000). The process of dying and the prospect of death are ever-present reminders of our mortality and vulnerability to senescence and physical decline. Ultimately, death represents the antithesis of biological integrity inasmuch as the mechanisms that sustain us in life eventually succumb to the dictates of our biological inheritance.

Accordingly, the diseases and conditions associated with a terminal diagnosis are likely to be understood first through a biomedical perspective, which focuses on pathology, prognosis, and treatment (Rothschild, 1997). However, Steinhauser, Clipp, and colleagues (2000) emphasized the importance of viewing

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the dying person less as a disease to be treated and more as a person living within a rich and multidimensional life context. Lynn (1997) underscored this sentiment by noting that "paying attention to the *person* may be more important than the medical problem" (p. 1633).

Albeit a natural and expected part of our existence, death is still viewed as failure—an affront to modern medical science. Although we are the beneficiaries of remarkable advances in modern health care, the prospect of death remains; moreover, the very nature of dying has changed (Muir & Arnold, 2001). The chronic conditions of the 21st century (e.g., heart disease and cancer) (Emanuel & Emanuel, 1998; also see Nicassio & Smith, 1995) may be associated with prolonged illness and extended survival, resulting in weeks, months, or even years to prepare for death (Walter, 1996).

Given the life-sustaining treatments available in the face of incurable disease, the issues confronting the dying person may also be changing (see Table 1). Concerns raised by terminally ill individuals include physical issues (e.g., Rothschild, 1997), cognitive and emotional problems, decisions regarding treatment (von Gunten, Ferris, & Emanuel, 2000), and preparations for the end of life (Miller & Fins, 1996; Steinhauser, Clipp, et al., 2000). In addition, concerns about family members and relationships are likely to emerge (Block, 2001), coupled with fears and anxieties regarding death itself (Cobb, 2001).

Amid this milieu of biomedical, social-emotional, and logistical end-of-life concerns are clear expressions of spiritual need (Cherny, Coyle, & Foley, 1994a, 1994b, 1996; Emanuel & Emanuel, 1998). Kearney and Mount (2000) argued that spiritual issues are central to the human crisis that develops following a terminal diagnosis; nevertheless, modern medicine fails to effectively treat the patient by ignoring this spiritual dimension. Biomedicine in itself is insufficient to assess and support the whole person as she or he prepares for the final stage of life. Kubler-Ross (1975) established an "emotional trajectory" of dying and recognized the importance of social-emotional and spiritual-religious dimensions as part of a multidisciplinary approach to patient care, including physicians, nurses, family, and spiritual care providers.

The tenets of palliative medicine embrace this multidimensional nature of the dying person, emphasizing the integration of physical, psychological, social, and spiritual elements of life (Bradshaw, 1996; Clark, 1999; Kearney & Mount, 2000; Masera et al., 1999; Rothschild, 1997). Medical science and technology have traditionally focused on the disease, whereas the patient's own experience of illness requires a broader perspective, including spiritual issues, to understand the whole patient (Kearney & Mount, 2000). However, spiritual dimensions of humanity are often poorly defined, even vague and nebulous. Therefore, the inclusion of spirituality within the biomedical context of dying requires a closer inspection of what is meant by this concept. The emphasis here must be to help the dying person navigate her or his own personal spiritual landscape in a way that promotes acceptance of life and preparation for death.

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**TABLE 1: A Sample of Concerns Among the Terminally Ill at the End of Life**

| *Issue* | *References Mentioning this Issue* |
|---|---|
| Physical | |
| Pain and its treatment | Rothschild, 1997; Severson, 1997; Singer, Martin, & Kelner, 1999; Steinhauser, Christakis, et al., 2000 |
| Lack of energy/fatigue | Cherny, Coyle, & Foley, 1994a; Rothschild, 1997 |
| Cleanliness | Steinhauser, Christakis, et al., 2000 |
| Nausea and vomiting | Cherny et al., 1994a; Rothschild, 1997 |
| Dyspnea and suffocation | Emanuel & Emanuel, 1998; Rothschild, 1997 |
| Prolongation of dying | Singer et al., 1999 |
| Cognitive-affective | |
| Anxiety and panic | Block, 2001; Cherny et al., 1994a; Severson, 1997 |
| Fear | Block, 2001; Cherny et al., 1996; Moadel et al., 1999; Rothschild, 1997 |
| Depression | Cherny et al., 1994a, 1996; Shuster, Breitbart, & Chocinov, 1999 |
| Delirium | Cherny et al., 1994a |
| Mental awareness | Steinhauser, Christakis, et al., 2000 |
| Social | |
| Family relationships | Block, 2001; Singer et al., 1999 |
| Concern over family burden | Singer et al., 1999; Stewart, Teno, Patrick, & Lynn, 1999 |
| Sharing time with friends | Steinhauser, Christakis, et al., 2000 |
| Communication | Stewart et al., 1999 |
| Planning and decision making | |
| Advance care planning | Lynn, 1997; von Gunten, Ferris, & Emanuel, 2000 |
| Economic concerns | Emanuel & Emanuel, 1998; Stewart et al., 1999 |
| Legal and financial issues | Block, 2001; Steinhauser, Christakis, et al., 2000 |
| Funeral/postdeath events | Block, 2001; Steinhauser, Clipp, et al., 2000 |
| Existential and spiritual | |
| Beliefs about life and death | Lyon, Townsend-Akpan, & Thompson, 2001 |
| Transcendence | Stewart et al., 1999 |
| Existential distress | Cherny et al., 1994a, 1994b |
| Unmet spiritual needs | Moadel et al., 1999 |
| Meaning of pain/suffering | Block, 2001 |
| Meaning of life | Moadel et al., 1999; Thomas & Retsas, 1999 |
| Peace with God | Steinhauser, Christakis, et al., 2000 |

NOTE: The issues included here were not necessarily the primary emphases of the corresponding references but were derived from the content of these articles.

## DEFINING SPIRITUALITY: INTEGRATING RELIGIOUS AND SECULAR IDEOLOGIES

### RELIGIOUS PERSPECTIVES

The notion of spirituality is clearly important to many people facing death (Cherny et al., 1994a, 1994b; Emanuel & Emanuel, 1998; Moadel et al., 1999; Steinhauser, Christakis, et al., 2000). Despite its prevalence in the literature, the

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relative eclecticism evident in defining this concept may undermine its utility as a helpful construct in end-of-life care. Given the diverse ideas associated with spirituality, a conceptual framework is needed that reflects points of connectedness between traditional religious theology and growing secular perspectives (e.g., Walter, 1993, 1996).

Kearney and Mount (2000) suggested that the nature of spirituality is most readily reflected in religious tradition, which is a source of meaning for billions of people around the world (Paulson, 2001). The history, ritual, and sacred writings associated with religious beliefs provide direction and purpose in life and may serve as a critical source of strength and structure as death approaches (Daaleman & VandeCreek, 2000). Steinhauser, Christakis, and colleagues (2000), in a study of seriously ill and bereaved family members, reported that "being at peace with God" was considered important to nearly 90% of respondents. Such a finding underscores the importance of belief in a higher power and reflects the need for reconciliation with God as one prepares to die (also see Kellehear, 2000).

The respect for religious belief and a recognition of its supportive role in the end-of-life context are principles on which modern hospice was founded (Bradshaw, 1996; Cobb, 2001). Holistic (i.e., whole person) care respects the synergy between body, mind, social, and spiritual elements of the person (Mauritzen, 1988) and was specifically influenced by Christian theology. The historical Jesus Christ demonstrated respect for the physical needs of humanity yet emphasized the ultimate importance of one's spiritual condition and relationship with God. His life and death as recorded in Biblical scripture exemplify this relationship between the needs and limitations of the physical body and the hope of spiritual transcendence beyond suffering and death.[1]

Appreciating a dying person's religious beliefs regardless of specific theology or doctrine may be central in defining his or her understanding of spirituality. Religion promotes meaning and hope (Moadel et al., 1999; Pavelis, 1997) and may be the principal source of strength when confronting the challenges posed by the realization of mortality (e.g., Lyon, Townsend-Akpan, & Thompson, 2001). Theological constructs serve not only as a framework for coping with a terminal condition but also offer a connection with something greater than oneself. In this regard, a relationship with a higher power or a reliance on religious ritual (Lyon et al., 2001) may be the primary means of spiritual expression. A religious dimension of spirituality, as noted by Kellehear (2000), may be most evident in the need for religious reconciliation and forgiveness, a dependence on religious rites and sacraments, and visits by clergy who offer support through religious/sacred literature and prayer.

## SPIRITUALITY AND SECULAR BELIEFS

Although systematic theology may define spirituality for many religious believers, this perspective may fail to support those who do not embrace a

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specific religious tradition (e.g., Walter, 1993, 1996). Accordingly, the question has been asked, "Can spirituality exist without theology?" (i.e., without a systematic study of God) (e.g., Cobb, 2001). Fundamentally, the deeper issue may be to define spirituality in a way that respects religious theology yet provides a spiritual view that accepts those who profess distinctly nontheological beliefs.

Mauritzen (1988) suggested that spirituality may not require a purely religious perspective but represents the dimension that contributes to the core of a person's being. In this way, spiritual identification requires an examination of the essence of one's self and existence (e.g., Thomas & Retsas, 1999) predicated in part on the integration of biological, psychological, and social resources. Interestingly, each of these areas is represented in the concerns expressed among dying persons (see Table 1), reflecting the very essence of one's spirituality "besieged" by pathology, as observed in physical diminution, psychological distress, and impacted social relationships. Spirituality, therefore, may be viewed as a gestalt—the summation of diverse aspects of life that collectively gives meaning to each person's existence (Chaplain R. Shores, personal communication, January 31, 2002). As noted by Mauritzen, it may be defined as the "agent" that infuses the biological, psychological, and social aspects of life (refer to Figure 1A), transcending and uniting these domains into our very sense of existence.

Spirituality enables a healthy and active investment in life and provides the resources through which we respond to infirmity, physical decline, and approaching death. It may not depend on systematic theology but is present in each person's unique journey and spirit, where *spirit* reflects one's connectedness with others and a search for personal meaning (Chaplains L. Gregson & D. Engle, personal communication, February 14, 2002). Walter (1996) discussed the notion that everyone has their own "spiritual construct" through which they seek a sense of personal identity and meaning. This construct may be likened to a lens through which the images and experiences of life are focused while also permitting a projection of self—both present and hoped for—into the future, even beyond death. If, as some asserted, "the final work of our lives is to make meaning of our life and come to terms with our death" (Irish, 1993, pp. 170-171), then this work must allow the dying person to make sense of his or her illness through his or her own spiritual construct.

The importance of finding meaning in life and constructing a framework of hope for the future emerges prominently in various perspectives of spirituality (Block, 2001; Targ, 2002; Thomas & Retsas, 1999). Mauritzen (1988) affirmed the essential nature of personal meaning as part of a spiritual framework and encouraged the inclusion of existential concepts when defining spirituality. Victor Frankl (1963, 1969), the author of "logotherapy" as a therapeutic expression of existential ideology, recognized the importance of personal meaning as a life-sustaining force (Paulson, 2001). The meaning we find in our lives may be derived from various external sources, including family, work, important causes, love of country, and God (see Walter, 1996). As such, meaning may be

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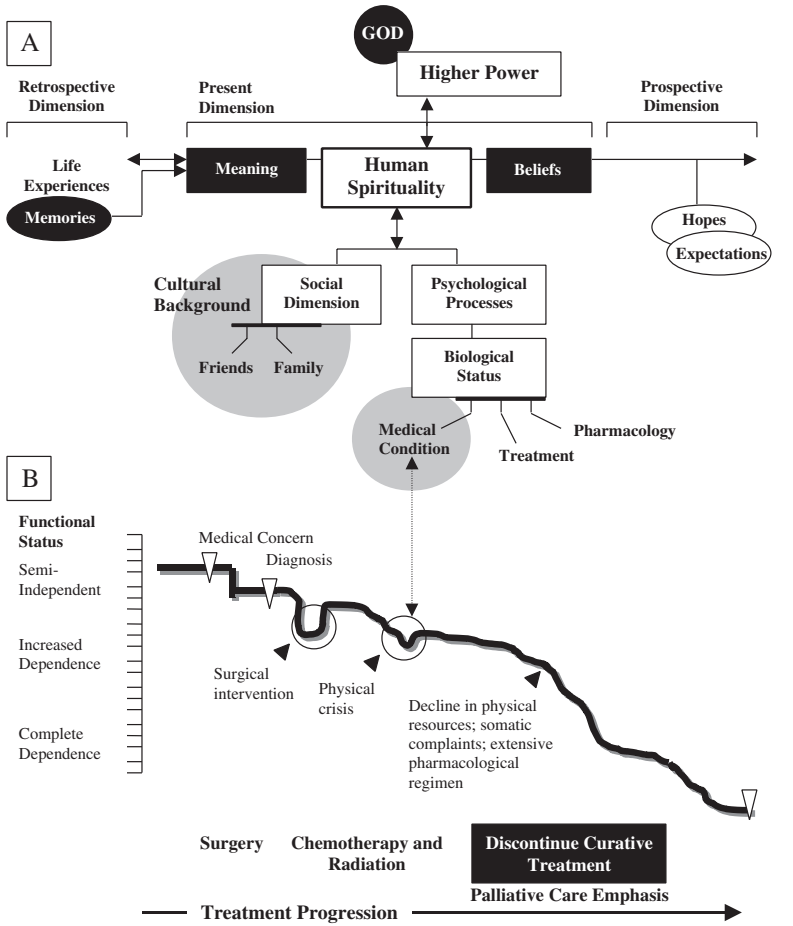


**Figure 1: Spiritual Assessment Within an End-of-Life Scenario**

*1A*. Many factors contribute to spirituality, which is traditionally viewed as a relationship with a higher power. The notion of meaning features prominently in spiritual definitions as derived in part from the important people, events, and accomplishments in a person's life. Memories (i.e., Retrospective Dimension) provide a historical context that may influence one's present spiritual dimension. The ability to deal with spiritual issues in the present may be affected by biological status, psychological processes (e.g., anxiety, cognitions, delirium, and depression), and social-cultural factors. Ultimately, a person's spiritual beliefs influence future hopes, fears, and expectations (i.e., Prospective Dimension).

*1B*. A hypothetical end-of-life trajectory, representing the progression of a disease as it affects physical resources and impairs functional independence is presented. A course of treatment is chronicled horizontally at bottom, reflecting an eventual transition from curative (e.g., chemotherapy and radiation) to palliative interventions. The dashed arrow linking Figures 1A and 1B illustrates a point of physical crisis consequent to changes in medical condition. The spiritual provider entering the scenario at this point would benefit from understanding the prior events and circumstances in this dying person's life. Moreover, recognizing the influence of medical, cognitive, and social-cultural factors on spiritual health and expression (i.e., Present Dimension) may offer important insights into the dying person's supportive resources and response to their terminal condition.

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defined in terms of one's relatedness to significant aspects of life, emerging out of a personal investment in the specifics of one's experience. In this way, the very act of remembering—recollecting the important and meaningful events of one's life (e.g., life review, see Cherny et al., 1994a, 1994b)—allows an entrance into the spiritual and may be similar to a sacred ritual itself (see Figure 1A, Retrospective Dimension).

## A BROAD CONCEPT OF SPIRITUALITY

Spirituality, therefore, can be conceptualized as a dimension of personhood defining the essence of humanity. It may be viewed through the lens of Cartesian duality (e.g., see Kearney & Mount, 2000), whereby the God-given spiritual element of life is present in yet distinctly different from physical existence. Alternatively, spirituality may be ascribed to a purely scientific or physical phenomenon emerging from the collective resonance of biological mechanisms. Indeed, a reductionist might argue that perceptions of self and spirituality merely reflect a biologically privileged pattern of neural architecture and activation (e.g., Cobb, 2001; Joseph, 2001; Teske, 2001).[2] Although religious and purely reductionist views of spirituality represent extreme positions along a spiritual beliefs continuum, a transcendent and relational notion of spirituality can embrace both perspectives. The conviction that we are ultimately connected to a greater force (e.g., physical or natural), higher power (e.g., God), or others around us defines this transcendent and relational nature of spirituality. Connecting with transcendent spirituality necessitates an inner-directed examination of the deepest and most sacred of human values but is also an outward- and forward-directed dimension, offering a sense of hope and anticipation of things yet to be.

The dying person's own definition of spirituality may be less philosophically articulated, founded rather on historical tenets (e.g., Christian, Jewish, and Islamic writings or scriptures), culturally transmitted values, social influences, and personal introspection. Nevertheless, the evidence of spirituality is likely to be expressed in observable attitudes, beliefs, and behavior. It is who we are in the present yet incorporates what we were in the past; moreover, spirituality is future directed and may be translated into this hope of transcendence beyond the finality of life (see Figure 1A). The elements of a dying person's spiritual self can be defined according to her or his present beliefs in the context of historical influences and personal perspectives on existence beyond death.

Searching for and defining spirituality in the life of a dying person requires more than simply asking "Do you consider yourself a spiritual person?" Understanding a person's spiritual nature necessitates moving through the dimensions of her or his life, carefully attending to and recognizing the behavioral, attitudinal, and relational evidence in support of spiritual identity and need. As described by one chaplain, spirituality is the definition of one's self, faith, and hope, not solely predicated on systematic theology but an indication of where

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the person is living in the present (Chaplain L. Gregson, personal communication, January 31, 2002).

## ASSESSING SPIRITUALITY

> The thought of putting science and spirituality together may at first appear a rather odd conjunction, for science deals in objective realism, and spirituality in the very soul of being. (Cobb, 2001, p. 19)
> [Dying] patients represent a failure of the institution in its life-sustaining role, and there is nothing in the system that provides for human nurturance to the soul when the body is beyond repair. (Kubler-Ross, 1975, p. 6)

In the modern approach to medical care for the dying, with its emphasis on disease, biomedicine (e.g., Rothschild, 1997; Steinhauser, Clipp, et al., 2000), and specializations in health care delivery (e.g., Cherny et al., 1994a), the issue of spirituality in end-of-life care may be formally assigned to persons with specific religious training or background (Cobb, 2001; Daaleman & VandeCreek, 2000; but see Thomas & Retsas, 1999). Today's hospitals have diverse staff specializing in the assessment and treatment of physical, psychological, and social distress in patients and families immersed in an end-of-life scenario (see Cherny et al., 1994a, pp. 65-66). Although medical personnel are encouraged to include a consideration of spiritual issues in their approach to patient care (e.g., Emanuel & Emanuel, 1998; Kagawa-Singer & Blackhall, 2001; Kellehear, 2000; Thomas & Retsas, 1999), local clergy and hospital chaplains may represent the specific source of spiritual care (Cobb, 2001; Kellehear, 2000; Mauritzen, 1988).

However, it is important to view spiritual care not as a compartmentalized feature of treatment but as an attitude that infuses the overall approach to whole-person care regardless of one's defined role in the care of a dying person. Kearney and Mount (2000) suggested that the delivery of optimal health care services to the dying must recognize the spiritual aspects of life, which is also reflected in recent models of patient assessment and treatment underscoring the influence of spiritual and existential needs on overall quality of life (Cherny et al., 1994a; Daaleman & VandeCreek, 2000; Lyon et al., 2001; Thomas & Retsas, 1999).

### ASSESSING SPIRITUALITY WITHIN THE BIOMEDICAL CONTEXT

A respect for the relevance of spirituality within a comprehensive care plan for the dying requires a broad understanding of spiritual issues and a working framework for assessing this dimension. Numerous summaries of the functional domains to consider when evaluating patient distress and quality of life refer to spiritual and religious beliefs and recognize the struggle individuals experience with the meaning of life and death (e.g., Block, 2001; Cherny et al., 1994a, 1994b, 1996; Emanuel & Emanuel, 1998). The conceptual framework for spirituality presented in Figure 1A essentially serves as a model for spiritual

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assessment when entering the life of a dying person. This framework minimizes attention to specific queries about religious or spiritual orientation while emphasizing the need to consider the multidimensional nature of a dying person's experience of ill health (e.g., Kearney & Mount, 2000). This approach emphasizes factors thought to influence the dying process (e.g., pathology, cognition, and social support) (Cherny et al., 1994a, 1996) and underscores the synergy between patient history, current life context, and her or his system of beliefs when arriving at a global assessment of spiritual status and needs.

Principally, this model suggests that spiritual assessment is best conceptualized within a comprehensive biomedical and social-contextual framework reflecting the "bio-psychosocial-spiritual" approach central to hospice and palliative care (see Bradshaw, 1996; Kearney & Mount, 2000). A complete model of spirituality and spiritual assessment must recognize the relationship between mind, body, and spirit and realize that a dying person's preparedness to examine spiritual issues may depend on their physical condition and their level of adaptation within their end-of-life context (see Figure 1B).

The principles of good palliative care integrate physical comfort (e.g., pain control) with attention to social-emotional support and spiritual concerns. Marrone (1999), in reviewing Abraham Maslow's need hierarchy, reinforced the interdependence of human needs in end-of-life treatment. Conceptually, lower levels of Maslow's hierarchy (e.g., biological needs) must be satisfied prior to reaching higher levels. Therefore, attaining the highest level of human functioning, which would include spiritual awareness and insight, depends on satisfying needs at more basic levels. Theoretically, the person struggling with fatigue, pain, or other somatic problems associated with disease may lack sufficient resources to explore spiritual issues. Ensuring physical comfort (e.g., pain management and attention to hydration and hunger) may enhance physical and cognitive status, thereby improving communication and enabling a more productive focus on social, emotional, and spiritual concerns (see Kearney & Mount, 2000). Cherny and colleagues (1994b) reinforced the relationship between physical needs and interventions with the dying by noting that "[as] long as patient comfort is adequately preserved there is potential for meaningful communication" (p. 75). Indeed, meaningful communication may be one of the most important elements in assessing the relevance of spiritual issues to the dying person and may be critical to the delivery of end-of-life care when spiritual concerns feature prominently in the person's life as she or he prepares to die.

## BEYOND THE BIOMEDICAL FRAMEWORK: PLACING SPIRITUAL ASSESSMENT WITHIN A WHOLE-PERSON PERSPECTIVE

A terminal condition can impose significant challenges to the resources of the body, resulting in diminished strength and physical endurance accompanied by depression or anxiety (e.g., Block, 2001; Cobb, 2001). Figure 1A emphasizes the effect of biomedical influences (e.g., nature of the disease, physical status,

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and medical-pharmacological regimens) on psychological and spiritual functioning; however, this does not reflect a perspective driven by a disease orientation, where the focus is on the person as a victim. Rather, the approach is predicated on recognizing the illness and its effects on the body, mind, and spirit but within the context of the person's life, values, and experiences (Steinhauser, Clipp, et al., 2000).

Steinhauser, Clipp, and colleagues (2000) noted that the professional provider (e.g., spiritual care person) may be at a disadvantage when initially meeting with a dying person inasmuch as she or he has only a cross-sectional perspective of the individual at one point in the dying person's illness. The provider may meet with a terminally ill person in response to a spiritual need or crisis yet lack a full appreciation of the present and historical illness context (refer to Figure 1B). The spiritual care specialist (e.g., clergy and chaplain) may not be the only person capable of addressing the spiritual needs of the dying (Ehman, Ott, Short, Ciampa, & Hansen-Flaschen, 1999; Post, Puchalski, & Larson, 2000), yet the involvement of medical personnel in the assessment and delivery of spiritual services remains questionable (e.g., see comment by Graner, 2000). Therefore, the spiritual needs of a dying person may be met most often through pastoral care referrals or visits from local clergy. Regardless of identity or role, the spiritual provider must be fully informed, cognizant of patient pathology and treatment issues (e.g., diagnosis, interventions, and physical crises), and aware of the intersection between the person's life context and the current point in their illness progression (Figure 1B).

A spiritual assessment must identify the elements of the dying person's life that inform and shape her or his dying experience (Figure 1A). Given that one cannot always anticipate the spiritual condition or convictions of a person struggling with a terminal condition, assessment of this domain requires a cautious respect for the potentially diverse associations people may have to the notion of spirituality. Concern for spiritual issues may intensify immediately after a terminal diagnosis or as death approaches (see Severson, 1997, Case 3; Stewart, Teno, Patrick, & Lynn, 1999), although some individuals may be estranged from religious beliefs and practices or may not have a specific tradition or personal philosophy. Given that spirituality is often associated with specific religious traditions, persons who affirm no such background may believe that spiritual issues have limited relevance for them.

A primary responsibility of the spiritual care provider may then be to simply "hear and accept" the dying person and assess how in tune she or he is with her or his self, life, and the world (Chaplain D. Engle, personal communication, February 14, 2002). Regardless of a person's specific religious adherence or philosophical perspective, the process of spiritual assessment necessitates the establishment of a relationship that facilitates communication and understanding. An appreciation of the person's culture and life context (Figure 1A) may facilitate this process inasmuch as these factors certainly shape the way people conceptualize illness and make meaning out of life and dying (Kagawa-Singer &

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Blackhall, 2001; for reviews, see Braun, Pietsch, & Blanchette, 2000; Irish, Lundquist, & Nelsen, 1993; also see Kubler-Ross, 1975). Specific questions regarding faith or spirituality (e.g., Block, 2001, p. 2899; Kagawa-Singer & Blackhall, p. 2995) may promote dialogue about spiritual or religious heritage, yet these queries may be most effective in situations where respondents have a specific religious or spiritual perspective on life and death.

Therefore, the focus does not have to be on religion, and for some it clearly will not. The objectives may be to recognize the person's sociocultural context (e.g., Kagawa-Singer & Blackhall, 2001), listen to her or his personal history, and understand her or his efforts to assign meaning to life and death. In addition, identifying the factors that can create or reduce distress and impact overall quality of life is important, including physical and psychological issues and relationships between the dying person, family, and health care providers (see Cherny et al., 1994a).

The assessment of spirituality as described here does not necessitate a formal diagnostic approach. Rather, a framework is needed for organizing information across life dimensions, coupled with a perspective for conceptualizing the circumstances surrounding a person's dying. The concept of spirituality and the approach to spiritual assessment offered here (Figure 1) represents one attempt to organize such a framework for exploring the spiritual needs and concerns of the dying patient. Ultimately, successful spiritual care will depend on the provider's ability to establish a presence with the dying person. This presence, both physical and emotional, fosters a connection through which the spiritual elements of a person's life can be assessed and expressed. One hospice chaplain has referred to such "assessment" as analogous to a "gut reaction" that cannot be constrained by artificial boundaries or systematic interviews, requiring an immersion in the dying person's whole being (Chaplain D. Engle, personal communication, February 14, 2002). This requires sensitivity to the information embedded in the multiple dimensions of a person's illness and an awareness of where along the end-of-life trajectory the spiritual provider enters into the context.

## SPIRITUAL CARE DELIVERY NEAR THE END OF LIFE

The inclusion of spirituality in the assessment and delivery of services to persons near the end of life is an important part of holistic care (Kearney & Mount, 2000). Entering into the life and circumstances of the dying person is not only the first step in assessing spiritual beliefs and needs but is the critical dimension of practicing spiritual care. As one enters into a relationship with a dying person, the incorporation of a spiritual attitude must of necessity be free of any

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proselytization (Mauritzen, 1988). This ethical imperative mandates that the values and beliefs of the dying person and family are respected and accepted, with no attempt on the part of the spiritual care provider to impose her or his own beliefs (Smith, 1993).

Accordingly, the spiritual care provider must be prepared to enter into an accepting relationship with the dying person, thereby allowing an opportunity for personal contact and supportive communication regardless of professed faith or beliefs. Kearney and Mount (2000) asserted that an important response to the identification of spiritual pain in the dying person is the establishment of personal contact, which promotes the validation of the dying patient's personhood. It is noteworthy that the application of a spiritual perspective is predicated on a belief that connectedness provides a means through which spirituality can be experienced. Spirituality is viewed as relational, involving relationships with others and with "God as [one sees] God," and as action oriented, involving the interactional part of one's being (Chaplain L. Gregson, personal communication, January 31, 2002). As such, the spiritual provider may need to help a person act in ways that promote spiritual completeness. These actions may involve prayer, reading scripture or religious literature (e.g., Kellehear, 2000), the use of ritual or symbolism (e.g., Lyon et al., 2001), seeking out relationships and reconciliation (e.g., Kellehear, 2000), or simply exploring one's life, values, and anticipation of life beyond death.

A spiritual intervention is not necessarily different from certain approaches to counseling. However, unlike traditional counseling methods, death represents a problem with no solution, with the spiritual intervention focused on recognizing resources in the dying person and facilitating their application (Chaplain L. Gregson, personal communication, January 31, 2002). Here, spirituality intersects with existential theory and practice (Frankl, 1963, 1969), which underscores the importance of exploring sources of personal life meaning. The spiritual care provider, by helping the dying person remember and explore a lifetime of experiences, may use these memories as windows to the soul, revealing images reflecting the meaningful elements of a person's life (Retrospective Dimension in Figure 1A).

The spiritual care provider must ultimately be a presence who respectfully enters into the dying person's experience, affirming and accepting her or his identity, encouraging her or his search for meaning, and allowing for a discussion of fears and hopes concerning existence beyond this life. The value of spiritual care may be in helping the dying person recognize or otherwise experience the spiritual dimension of life as she or he prepares to die. Where possible, this may involve facilitating the sense of integration between one's past (e.g., accomplishments, activities, and behaviors), present (e.g., family and friends, beliefs, and values), and future legacy, which will live on with others—essentially a search for meaningfulness in the final stages of life.

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## CONCLUSION

The spiritual quest for meaning is borne out of an appreciation of the multidimensional nature of the human spirit. It is a process, a journey that begins with the spiritual provider's presence with the dying person and her or his witness to the struggles, adaptations, and movement toward the end of life. The idea of a good or healthy death (e.g., Emanuel & Emanuel, 1998; Smith & Maher, 1991) may be incompatible with prevailing notions of death as failure; however, the holistic care perspective, with its respect for spiritual awareness, may be essential in managing death anxiety and spiritual pain (Cobb, 2001; Kearney & Mount, 2000), thereby promoting spiritual health near the end of life.

## NOTES

1. Bradshaw (1996) referred to the recorded words of Jesus in Biblical scripture as the foundation for the hospice approach to human care: "For I was hungry and you fed me; I was thirsty and you gave me water; I was a stranger and you invited me into your homes; naked and you clothed me; sick and in prison, and you visited me" (Matthew 25:35-36, *The Living Bible*). Jesus attended to the physical needs of the sick and infirm yet promoted spiritual goals, emphasizing the distinction between the physical body and the soul (Matthew 10:28). In His own struggle with impending death (Matthew 26:36-45) and the very process of dying (Ludwig, 1989) is recorded his experience of physical need and suffering yet evidence of a reliance on a higher source of strength (i.e., God) and the belief in life beyond earthly suffering and death.

2. Teske (2001) suggested that spirituality is a function of neurodevelopmental architecture (e.g., prefrontal cortex and limbic system) and social-environmental contingencies influencing spiritual expression. According to Joseph (2001), the neurological foundations of religious experience include the amygdala, limbic system, and temporal lobes. Religious experience, therefore, may be viewed as an emergent property of neural ensembles and patterned activity resulting in emotional and visual effects (e.g., visions and intensely spiritual-emotional experiences).

## REFERENCES

Block, S. D. (2001). Psychological considerations, growth, and transcendence at the end of life: The art of the possible. *Journal of the American Medical Association*, *285*, 2898-2905.

Bradshaw, A. (1996). The spiritual dimension of hospice: The secularization of an ideal. *Social Science and Medicine*, *43*, 409-419.

Braun, K. L., Pietsch, J. H., & Blanchette, P. L. (Eds.). (2000). *Cultural issues in end-of-life decision making*. Thousand Oaks, CA: Sage.

Cherny, N. I., Coyle, N., & Foley, K. M. (1994a). Suffering in the advanced cancer patient: A definition and taxonomy. *Journal of Palliative Care*, *10*, 57-70.

Cherny, N. I., Coyle, N., & Foley, K. M. (1994b). The treatment of suffering when patients request elective death. *Journal of Palliative Care*, *10*, 71-79.

Cherny, N. I., Coyle, N., & Foley, K. M. (1996). Guidelines in the care of the dying cancer patient. *Pain and Palliative Care*, *10*, 261-286.

Clark, D. (1999). "Total pain," disciplinary power and the body in the work of Cicely Saunders, 1958-1967. *Social Science & Medicine*, *49*, 727-736.

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Cobb, M. (2001). *The dying soul: Spiritual care at the end of life*. Philadelphia: Open University Press.

Daaleman, T. P., & VandeCreek, L. (2000). Placing religion and spirituality in end-of-life care. *Journal of the American Medical Association*, *284*, 2514-2517.

Ehman, J. W., Ott, B. B., Short, T. H., Ciampa, R. C., & Hansen-Flaschen, J. (1999). Do patients want physicians to inquire about their spiritual or religious beliefs if they become gravely ill? *Archives of Internal Medicine*, *159*, 1803-1806.

Emanuel, E. J., & Emanuel, L. L. (1998). The promise of a good death. *Lancet*, *351*(Suppl. II), SII21-SII29.

Frankl, V. (1963). *Man's search for meaning*. New York: Pocket Books.

Frankl, V. (1969). *The will to meaning*. New York: Signet.

Graner, J. (2000). Physicians and patient spirituality. *Annals of Internal Medicine*, *133*, 748.

Irish, D. P. (1993). Reflections by professional practitioners. In D. P. Irish, K. F. Lundquist, & V. J. Nelsen (Eds.), *Ethnic variations in dying, death, and grief: Diversity in universality* (pp. 163-179). Washington, DC: Taylor & Francis.

Irish, D. P., Lundquist, K. F., & Nelsen, V. K. (Eds.). (1993). *Ethnic variations in dying, death, and grief: Diversity in universality.* Washington, DC: Taylor & Francis.

Joseph, R. (2001). The limbic system and the soul: Evolution and the neuroanatomy of religious experience. *Zygon*, *36*, 105-136.

Kagawa-Singer, M., & Blackhall, L. J. (2001). Negotiating cross-cultural issues at the end of life: "You got to go where he lives." *Journal of the American Medical Association*, *286*, 2993-3001.

Kearney, M., & Mount, B. (2000). Spiritual care of the dying patient. In H. M. Chochinov & W. Breitbart (Eds.), *Handbook of psychiatry in palliative medicine* (pp. 357-373). Oxford, UK: Oxford University Press.

Kellehear, A. (2000). Spirituality and palliative care: A model of needs. *Palliative Medicine*, *14*, 149-155.

Kubler-Ross, E. (1975). *Death: The final stage of growth*. Englewood Cliffs, NJ: Prentice Hall.

Ludwig, C. (1989). *At the cross*. Anderson, IN: Warner Press.

Lynn, J. (1997). An 88-year-old woman facing the end of life. *Journal of the American Medical Association*, *277*, 1633-1640.

Lyon, M. E., Townsend-Akpan, C., & Thompson, A. (2001). Spirituality and end-of-life care for an adolescent with AIDS. *AIDS Patient Care and STDs*, *15*, 555-560.

Marrone, R. (1999). Dying, mourning, and spirituality: A psychological perspective. *Death Studies*, *23*, 495-519.

Masera, G., Spinetta, J. J., Jankovic, M., Ablin, A. R., D'Angio, G. J., Van Dongen-Melman, J., et al. (1999). Guidelines for assistance to terminally ill children with cancer: A report of the SIOP working committee on psychosocial issues in pediatric oncology. *Medical and Pediatric Oncology*, *32*, 44-48.

Mauritzen, J. (1988). Pastoral care for the dying and bereaved. *Death Studies*, *12*, 111-122.

Miller, F. G., & Fins, J. J. (1996). A proposal to restructure hospital care for dying patients. *New England Journal of Medicine*, *334*, 1740-1742.

Moadel, A., Morgan, C., Fatone, A., Grennan, J., Carter, J., Laruffa, G., et al. (1999). Seeking meaning and hope: Self-reported spiritual and existential needs among an ethnically-diverse cancer patient population. *Psycho-Oncology*, *8*, 378-385.

Muir, J. C., & Arnold, R. M. (2001). Palliative care and the hospitalist: An opportunity for cross-fertilization. *American Journal of Medicine*, *111*(9B), 10S-14S.

Nicassio, P. M., & Smith, T. W. (Eds.). (1995). *Managing chronic illness: A biopsychosocial perspective*. Washington, DC: American Psychological Association.

Paulson, D. S. (2001). The hard issues of life. *Pastoral Psychology*, *49*, 385-394.

Pavelis, K. W. (1997). Hope: Critical therapy. *Journal of Musculoskeletal Rehabilitation*, *8*, 237-239.

Downloaded from abs.sagepub.com at PENNSYLVANIA STATE UNIV on May 16, 2016

Post, S. G., Puchalski, C. M., & Larson, D. B. (2000). Physicians and patient spirituality: Professional boundaries, competency, and ethics. *Annals of Internal Medicine*, *132*, 578-583.
Rothschild, S. K. (1997). Medical care of the dying patient. *Medical Update for Psychiatrists*, *2*, 62-66.
Severson, K. T. (1997). Dying cancer patients: Choices at the end of life. *Journal of Pain and Symptom Management*, *14*, 94-98.
Shuster, J. L., Breitbart, W., & Chocinov, H. M. (1999). Psychiatric aspects of excellent end-of-life care. *Psychosomatics*, *40*, 1-4.
Singer, P. A., Martin, D. K., & Kelner, M. (1999). Quality end-of-life care: Patients' perspectives. *Journal of the American Medical Association*, *281*, 163-168.
Smith, D. C. (1993). Exploring the religious-spiritual needs of the dying. *Counseling and Values*, *37*, 71-77.
Smith, D. C., & Maher, M. F. (1991). Healthy death. *Counseling and Values*, *36*, 42-48.
Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *Journal of the American Medical Association*, *284*, 2476-2482.
Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M., & Tulsky, J. A. (2000). In search of a good death: Observations of patients, families and providers. *Annals of Internal Medicine*, *132*, 825-832.
Stewart, A. L., Teno, J., Patrick, D. L., & Lynn, J. (1999). The concept of quality of life of dying persons in the context of health care. *Journal of Pain and Symptom Management*, *17*, 93-108.
Targ, E. (2002). Healing HIV: Mind, body, and spirit. *Focus*, *17*(2), 1-4.
Teske, J. A. (2001). Neuroscience and spirit: The genesis of mind and spirit. *Zygon*, *36*, 93-104.
Thomas, J., & Retsas, A. (1999). Transacting self-preservation: A grounded theory of the spiritual dimensions of people with terminal cancer. *International Journal of Nursing Studies*, *36*, 191-201.
von Gunten, C. F., Ferris, F. D., & Emanuel, L. L. (2000). Ensuring competency in end-of-life care: Communication and relational skills. *Journal of the American Medical Association*, *284*, 3051-3057.
Walter, T. (1993). Death in the new age. *Religion*, *23*, 127-145.
Walter, T. (1996). Developments in spiritual care of the dying. *Religion*, *26*, 353-363.

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