

# Spirituality and Uncertainty at the End of Life

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**S**pirituality is a human quality that intensifies during times of crisis, such as the end of life (EOL). Understanding the quality of spirituality has been a focus of EOL care for some time; however, the literature is limited as to how the quality of spirituality is reported for people at the EOL. The majority of reports portray spirituality at the EOL as either contributing to health (spiritual well-being or integrity) or detracting from it (spiritual distress or pain) (Buxton, 2007; Deal, 2011; Frankl, 1959; McClain, Rosenfeld, & Breitbart, 2003). That oversimplifies spirituality by suggesting that it has a dichotomous nature with limited outcomes, which is incongruent with the dynamic nature of spirituality widely reported in the literature (Dobratz, 2005). Previous research conducted by the first author of the current article identified uncertainty as another way that terminally ill individuals experience spirituality (Stephenson, Draucker, & Martsof, 2002). The current article will examine the congruency between uncertainty and spirituality as experienced at the EOL to ascertain whether they overlap to form the single, unique concept of spiritual uncertainty.

## Background and Significance

Spirituality at the EOL is most notably described as the search for meaning and purpose that unfolds throughout life and culminates in varying degrees of self-transcendence (Martsof & Mickley, 1998; Reed, 1991; Stephenson et al., 2002). Inherent in the search for meaning is the interpretation of beliefs, values, and relationships that play important roles in how people experience dying (Dyess, 2011). Spirituality is important for people nearing the EOL (Abbas & Dein, 2011) but has been difficult for researchers, clinicians, and patients to articulate.

The majority of research about uncertainty centers around Mishel's (1988, 1990) theory of uncertainty in illness. Mishel (1988) defined uncertainty as, "A cognitive state created when the person cannot adequately structure or categorize an event because of the lack of sufficient cues" (p. 225). The theory of uncertainty in illness asserts that uncertainty is a cognitive state that occurs

**Purpose/Objectives:** To examine the theoretical congruency between uncertainty and spirituality at the end of life (EOL).

**Data Sources:** Relevant empirical and theoretical articles using the key words *spirituality*, *uncertainty*, *terminal illness*, and similar derivatives were drawn from the databases of CINAHL<sup>®</sup>, MEDLINE<sup>®</sup>, PsycINFO, and SocINDEX.

**Data Synthesis:** Spirituality and uncertainty were compared for theoretical congruency based on five general categories: prevalence, temporality, interpretation, quality, and directionality. The categories were drawn from the uncertainty literature and looked at the ability of spirituality and uncertainty to contribute to or detract from health.

**Conclusions:** This article presents an innovative way of viewing how spirituality is experienced at the EOL. The likelihood that uncertainty and spirituality can coexist as a simultaneous and even blended construct that influences the EOL is supported and warrants additional exploration.

**Implications for Nursing:** Health professionals must recognize the prevalence of spiritual uncertainty in the lives of their patients and understand the need to frequently assess for spiritual uncertainty. Specific recommendations are provided to guide professionals in addressing spiritual uncertainty with patients.

**Key Words:** spirituality, religiousness, end-of-life

when patients cannot perceive the meaning of their illness as a result of the individual, formalized structure by which it is framed (Mishel, 1988, 1990). If an individual does not have an existing schema or reference point, meaning cannot be derived for the event, which leads to uncertainty. The theory of uncertainty in illness has been tested on several chronically and acutely ill cohorts, including patients with prostate cancer (Bailey et al., 2011), breast cancer (Mishel et al., 2005), and hepatitis C (Bailey et al., 2010); however, no studies were identified that tested the theory of uncertainty in illness with adults at the EOL. Dying from a terminal illness is complex, unpredictable, and lacks an appropriate schema based on previous life experience. Therefore, the experience of terminal illness could be particularly prone to uncertainty.

The amount of research focusing on uncertainty at the EOL is limited. McKechnie, Macleod, and Keeling

(2007) conducted research using a phenomenologic approach on seven patients who were terminally ill to understand their experiences with dying. Findings revealed that uncertainty was an emergent theme from the stories that participants told, and included uncertainties about their diagnosis and treatment.

Other researchers reported incidental findings about uncertainty, including how hospice patients used resilience to maintain well-being in the face of uncertainty (Nelson-Becker, 2006) and the difficulties experienced by patients and families because of uncertainty at the EOL (Gardner & Kramer, 2009). No studies were found that sought to directly examine uncertainty in the context of spirituality.

Previous research conducted by the first author of the current article used qualitative interviews from hospice patients to explore the experience of spirituality at the EOL (Stephenson et al., 2002). A subsequent theme that emerged from that data, in addition to that of spirituality, was uncertainty. Participants made numerous comments about the doubts and questions they had about spirituality. For example, when one participant was asked what he thought was the reason for his terminal illness, he stated,

Well, about His wish, I couldn't tell you. Only God knows what it is. . . . He's got cut out for you. Whether He wants me or not . . . I don't know if He wants me or not, but I don't want to give up hope (p. 54).

Similar statements pertaining to uncertainty about spirituality were shared by other participants, indicating that uncertainty was a salient theme for that sample population.

Previous research implied that a relationship may exist between uncertainty and specific spiritual attributes. For example, Nelson-Becker (2006) reported that uncertainty complicated the process of separating from important connections and questioned beliefs. Gardner (2008) conducted qualitative interviews with 35 couples in which one partner was terminally ill. "Living with uncertainty" was identified as a major theme in which dealing with the unknown influenced the couples' searches for meaning, beliefs, and connections with others.

Bern-Klug (2004) described the *ambiguous dying syndrome* as occurring when death was certain but its timing was not. The inability to predict when death will come leaves many opportunities for questions and doubts, which can directly interfere with the dying individual's ability to prepare for death. For example, feeling time slip away causes some to seek additional treatment, whereas others will stop. These individualized reactions to dying must be understood by health professionals, whose patients rely on them for support. Gardner (2008) associated the ambiguity of dying and search for meaning as struggles faced by terminally ill patients and their families. Each of these processes il-

lustrates the dynamic nature of spirituality that can be affected by the presence of uncertainty.

Spiritual care is important for patients nearing the EOL (Abbas & Dein, 2011). Providing spiritual care that does not include an understanding of the role of uncertainty may be incomplete and risks depriving patients of the best possible outcomes for a peaceful death. Before additional research is conducted, however, an analysis of uncertainty and spirituality is needed to determine if a single, unique concept of spiritual uncertainty exists. The purpose of the current article is to examine the congruency of spirituality and uncertainty at the EOL and consider the role that uncertainty plays in spiritual care.

## Reviewable Concepts

Conducting a comparative analysis between uncertainty and spirituality is challenging because each phenomenon rests at a different level of abstraction. Concepts deemed too abstract to be easily observable on their own are regarded as constructs (Jacox, 1974). Uncertainty is considered to be a concept, but spirituality is regarded as a construct too abstract to be observed by itself (McEwen, 2011). Spirituality is best conceptualized by reducing it into lower-level concepts that comprise its essence. Therefore, before a direct comparison between uncertainty and spirituality can be made, spirituality must be reduced into common lower-level concepts or attributes that shape the construct and constitute its essence. A literature review of research conducted from 2002–2012 was performed to determine how spirituality at the EOL was described by researchers (Stephenson & Berry, 2013). Findings revealed that researchers most often used the attributes of meaning, connecting, belief, self-transcendence, and value to describe the essence of spirituality (Stephenson & Berry, 2013). Therefore, for the current article, spirituality is described as the integration of these five common attributes, which serve as lower-level concepts of spirituality, so that spirituality and uncertainty can be compared on similar levels of abstraction. Table 1 describes each spiritual attribute as it contributes to the construct of spirituality at the EOL.

## Direct Comparisons

The comparison between uncertainty and spirituality started with uncertainty. Spirituality was compared against uncertainty based on five general categories. Three categories (prevalence, temporality, and interpretation) were selected for review because they represented the key attributes of uncertainty as drawn from the literature (McCormick, 2002; Penrod, 2001). Quality also was included to evaluate whether uncertainty and spirituality were contributors or deterrents of health. Directionality was included to determine whether uncertainty and spirituality influenced one another and,

**Table 1. Descriptions of Common Spiritual Attributes as Identified in the Literature**

Criterion	Spiritual Attributes
Beliefs	Refers to the conviction in the truth of something closely intertwined with faith and hope.
Connecting	Refers to shared relationships with self, others, a higher power, and the environment, which can lead to personal growth.
Meaning	Refers to making sense of life's unfolding and finding purpose in existence; the primary motivational force of man.
Self-transcendence	Refers to a mystical connection with others and the universe that arises from a process of expanding personal boundaries and is experienced as wholeness, empowerment, maturation, and well-being.
Value	Refers to all that is precious and worthy of high priority.

*Note.* Based on information from Buxton, 2007; Dyess, 2011; Frankl, 1959; Haase et al., 1992; Hermann, 2006; Martsof & Mickley, 1998; Reed, 1991; Teixeira, 2008.

if so, whether the influence was one-directional or bidirectional.

The following sections will describe how uncertainty and spirituality are explained by each of these categories (prevalence, temporality, interpretation, quality, and directionality) and discuss the relationship between uncertainty and spirituality when applicable. Spirituality will be viewed as either an overarching construct or by the individual attributes that create its essence (meaning, connecting, belief, self-transcendence, and value).

### Prevalence

Uncertainty is a prevalent human occurrence experienced at many points throughout a lifetime (Mishel, 1990; Penrod, 2007). People with chronic illness experience uncertainties about their diagnosis, symptomatology, and prognosis (Coyle, 2002). Farber, Egnew, Herman-Bertsch, Taylor, and Guldin (2003) found that hospice patients lived with uncertainties, "which permeated every moment of their lives" (p. 21), supporting the likelihood that people at the EOL will experience uncertainty throughout the course of dying.

Spirituality is a prevalent experience that exists in everyone regardless of religious belief or affiliation. Even those who deny a connection with a higher power are believed to be spiritual because human and environmental connections and values are inescapable (Dobratz, 2005; Mendes, Trevizan, Ferraz, & Fávero, 2002). In addition, the search for meaning is central to every human endeavor and occurs on a daily basis (Frankl, 1959), and self-transcendence is viewed as a universal developmental process that affects everyone (Teixeira, 2008). Each of these spiritual attributes (connecting, meaning, self-transcending) illustrates how spiritual qualities are prevalent for all humans regardless of religious affiliation.

Uncertainty and spirituality are congruent in that both are prevalent throughout the lifetime. The prevalence with which spirituality and uncertainty occur independently increases the likelihood that they will eventually overlap and be experienced simultaneously

at some point during dying as terminally ill people develop questions about spirituality.

### Interpretation

Uncertainty is a subjective experience in which each event is interpreted for meaning, importance, and value. Uncertainty occurs when an event cannot be successfully interpreted because of a lacking schema (Clayton, Mishel, & Belyea, 2006). Similarly, if what was expected to happen is contrary to what actually does happen, the individual's ability to interpret the situation will be challenged (McCormick, 2002).

Spirituality, through the common attributes, is interpretive and, according to Reed (2009), a lifelong process that culminates in self-transcendence, depending how life events are interpreted. Illness and diagnosis may be interpreted by patients, caregivers, and loved ones as to the personal effect of each on spirituality. In addition, the interpretation of illness will change as symptoms come and go and new information is provided. Interpreting the meaning of illness and how it affects important connections, values, and beliefs is part of spirituality.

Uncertainty and spirituality are congruent in that they are subjective and individually interpreted for meaning. The best evidence of the relationship between uncertainty and spirituality is that meaning is a key feature of both. The fact that uncertainty arises from the inability to interpret meaning in an event (Mishel, 1988) and that meaning is one of the most frequently cited attributes of spirituality (Stephenson & Berry, 2013) suggests a close relationship between the two. Spiritual uncertainty may include questions or doubts about meaning; beliefs; connectedness; and values of life, illness, and dying.

### Temporality

Penrod (2001) described the temporality of uncertainty as being, "experienced in the present . . . affected by the past . . . and related to forecasts of the future," (p. 241).

The timing of an event influences how it is assessed, interpreted, and the degree to which uncertainty is assigned. Penrod (2007) asserted that time alone does nothing to improve uncertainty but does increase the likelihood of finding opportunities to process or work through the uncertain experience. To the contrary, not having sufficient time can leave one feeling lost and out of control.

Spirituality is temporal in nature, dynamic, and changes throughout one's lifetime. It may accelerate during times of crisis such as the EOL (Chao, Chen, & Yen, 2002; Sessanna, 2008; Shih et al., 2009). Spirituality changes depending on context, questioned beliefs, reprioritized connections, and a renewed search for meaning, which all stem from the realization that death is certain but timing is not. Elements of spirituality, such as with personal relationships, are fluid, and the EOL may be a time for re-evaluating the need for forgiveness and reconciliation in time for life's closure (Stephenson et al., 2002). Similarly, self-transcendence is a temporal process that may be accelerated as people move toward the EOL and, often, personal growth (Nelson-Becker, 2006).

Spirituality and uncertainty are similar in that they are temporal; fluctuate throughout the lifetime; and affect the past, present, and future (Agrimson & Taft, 2009; Penrod, 2001). For example, the need for forgiveness and reconciliation in personal relationships may be identified at the EOL. In addition, uncertainty and spirituality have the ability to change over time as old questions about spirituality are resolved and new questions arise. As spirituality and uncertainty change, new and sometimes unexpected dynamics are introduced into the EOL experience.

## Quality

According to Mishel (1988), uncertainty is neutral in itself but elicits a response with a positive or negative quality, depending how one interprets it and the extent to which the uncertain issue can be resolved or integrated into a revised world view. Viewing uncertainty positively facilitates personal growth by improving self-confidence or feelings of control (Penrod, 2007). Viewing uncertainty negatively, on the other hand, can elicit responses ranging from mild doubt to paralyzing fear (Penrod, 2007), and includes pain, discomfort, and suffering (Coyle, 2002).

Spirituality has either a positive or negative quality (to varying degrees) that may contribute to or detract from health, depending on how related events are perceived, their implications to individual outcomes, and how they influence the individual's current world view. Spirituality that contributes to health is reported as spiritual well-being or spiritual integrity, and consists of purpose and meaning, positivity, self-efficacy, optimism, comfort, faith, and belief in an afterlife (Buxton, 2007; Daaleman,

Emmett, Dobbs, & Williams, 2008; McClain et al., 2003; Mok, Wong, & Wong, 2010). People who report spiritual well-being are more apt to report social well-being, positive expressions of love and forgiveness, and improved quality of life. They are less likely to report depression, hopelessness, hastened death, and EOL despair (Breitbart et al., 2010; McClain et al., 2003; Prince-Paul, 2008). Low levels of spiritual well-being are associated with the desire for hastened death in people experiencing depression and psychological distress (Braam, Klinkenberg, & Deeg, 2011; McClain et al., 2003). Spirituality that detracts from health is reported as spiritual crisis, pain, and distress. A spiritual crisis occurs when a person is suddenly unable to make sense of their situation and resolution seems unlikely (Agrimson & Taft, 2009). Buxton (2007) found that patients acknowledging spiritual distress were struggling with their self-connections through a lost sense of identity and connections with others (e.g., concerns about family).

If uncertainty is a neutral concept that assumes a quality based on how one perceives it, spirituality will at least partially inform that perception. Uncertainty can arise out of spiritual questions of meaning, in which case the spiritual attribute is the source of uncertainty. For example, spirituality that exhibits a negative quality may cause an individual to approach an issue of uncertainty with anxiety and fear.

## Directionality

Directionality refers to the direction in which uncertainty and spirituality influence each other. Uncertainty affects spiritual beliefs when reasons for the illness are incongruent with expectations (Buxton, 2007). Nelson-Becker (2006) referred to this as "a liminal period of truth" (p. 99), in which patients who are terminally ill are compelled to reconstruct their spiritual world view to manage uncertainty and make sense of changing circumstances from terminal illness. Spirituality influences uncertainty, such as when spirituality mediates the resolution of uncertainty by facilitating meaning (positive influence) or when questions foster concerns that an illness is a punishment for a misdeed (negative influence)

Spiritual beliefs can ease uncertainties at the EOL or make them distressing. Prior research indicated that some people use spirituality to ease the stress they feel from uncertainty (Buck, Overcash, & McMillan, 2009; Tanyi, 2002). However, others' spiritual beliefs may frame illness as punishment for previous sins (Penrod, 2007). Therefore, the relationship between uncertainty and spirituality is reciprocal in that uncertainty and spirituality have the ability to influence how the other is experienced. The two are so closely intertwined that they must be regarded as a singular phenomenon that contributes to the dying experience.

## Exemplar: Lilly's Story

The authors believe that the theoretical congruence between spirituality and uncertainty has been demonstrated well enough to move forward and test how they interact within an unfolding exemplar. Lilly's story is derived from a combination of real-case scenarios and is based on the clinical and pastoral experiences of the authors. The construct of "spiritual uncertainty" will be used to illustrate the interplay and convergence of spirituality and uncertainty during the dying process.

Lilly was a 62-year-old Caucasian woman dying from advanced lung cancer. She described herself as religious and believed that "everything happens for a reason." As a child, she was raised to believe that things happened to reward good behaviors or teach valuable lessons. She never believed that God was a punishing God, but found herself questioning that belief at the EOL.

Lilly admitted to smoking cigarettes for 15 years when she was an adolescent and young adult but had not smoked in almost 35 years before her diagnosis of lung cancer. Now, she struggled with the meaning of having lung cancer, which seemed to be "a harsh way to learn a lesson." To Lilly, cancer felt like a punishment and, for the first time, she wondered whether God was punishing her for smoking when she was younger.

There were many times throughout my life when I would wonder how I would die and what would happen when I did. When my mother died of a stroke, I wondered, "Would that be me?" and when my father died from heart problems, I wondered, "Would that be how I would die?" Lung cancer never crossed my mind, but now that it's here and I am looking at it in the face, I can only ask "Why this?" I can't help but think there's a reason, but I don't know what it is—it makes no sense. You know, I used to smoke.

Lilly's closing statement acknowledging that she smoked offers a glimpse into her concern that smoking might be the reason she is dying from this disease.

Lilly was concerned about the welfare of her adult children who were exposed to secondhand smoke because she smoked in front of them when they were young. Lilly was becoming aware of the far-reaching implications of smoking and struggled with their meaning.

We never really took the risks from smoking seriously. We didn't even know about secondhand smoke back then. To come down with this cancer so long after I quit smoking is just unbelievable, and I pray that I haven't given cancer to my children. . . . My priorities were all messed up back then and we're all paying for it now.

Over the course of several weeks, Lilly was able to partially reconcile her uncertainties by remembering that "God is good," a remark that her mother would often share during difficult times.

Now and then, I can still hear my mother say that "God is good." It's something she would say all the time. She thought that you had to be patient and that we don't get to have all the answers. She would say, "That's what faith is for." So I've been trying to remember that; to really lean on my faith and not worry about the "how" I got here but focus on "what now."

### Exemplar Analysis

The prevalence of spiritual uncertainty is verified by Lilly's account of the numerous times she wondered about dying. Coping with terminal illness may provide opportunities for many questions and may accelerate spiritual thoughts. These two phenomena may understandably overlap at some point in time as uncertainties about spirituality emerge. That was true for Lilly, who found herself reconsidering lifelong beliefs and relationships, documenting not only the prevalence of spiritual uncertainty but also its temporality.

Lilly described a temporal spiritual transition in which fixed beliefs became fluid. For her, the past, present, and future aspects of her life conjoined to create a new world view that she was still trying to fully reconcile. She was in the process of reconsidering past beliefs within the context of her present situation to find meaning in her future.

Lilly's interpretation of her illness was crucial to how she experienced dying. Despite wondering about the cause of her death at different points of her life, Lilly never considered the possibility of lung cancer and what it would mean. Now that death was near, how she interpreted her uncertainty about meaning would directly influence her dying experience. For Lilly, uncertainty about meaning and beliefs started to negatively impinge on her ability to achieve the best possible EOL experience.

Lilly's story demonstrated the bidirectionality of spiritual uncertainty that impacted the quality of her dying experience. Initially, uncertainties influenced her spiritual beliefs, search for meaning, concerns about her children (connections), and values ("my priorities were all messed up"). Later, however, Lilly's spirituality influenced her uncertainties when she used spirituality to cope with her uncertainties by refocusing her attention on her faith rather than the unknown. Doing so changed the emotional quality of Lilly's situation and alleviated the distress she experienced from questions, blame, and guilt. Lilly's story exemplifies the salience of spiritual uncertainty in the lives of dying patients.

## Clinical Implications

The current analysis underscores the importance of health professionals who care for the terminally ill understanding the impact spiritual uncertainty can have on the dying process. Several clinical implications become apparent once spiritual uncertainty is viewed as a prevalent, interpreted phenomenon whose quality is influenced by temporal changes and directionality. Health professionals can recognize the prevalence of spiritual uncertainty in the lives of their patients and understand the importance of assessing for spiritual uncertainty. Relying on a single assessment of spiritual uncertainty is misleading and will not allow professionals to recognize changes in how patients question their spirituality. The temporal nature of spiritual uncertainty indicates that questions will change depending how life events are interpreted by patients. Health professionals who view spirituality according to the five spiritual attributes (meaning, beliefs, connecting, self-transcendence, and values) will recognize the vast array of spiritual issues that may arise during the dying process.

Clinicians should understand that spiritual uncertainty may be interpreted by patients with regard to the importance it has in their life and the degree to which it enhances or impedes a good death. Providers must be open to the vast array of spiritual issues about which people at the EOL can be uncertain. Noticing changes in a patient's point of view about spiritual uncertainty from visit to visit should not be challenged by clinicians but viewed as an opportunity for reflection. Rather than confronting patients about their changing views, clinicians should ask patients whether they might have changed the way they are viewing their situation. That opportunity enables clinicians and patients to engage in a dialogue about the patients' spiritual uncertainties and how they are affecting their living and dying.

Finally, health professionals must suspend their own interpretations of spiritual uncertainty and focus on the individual meanings of patients. They cannot assume spiritual uncertainty is necessarily good or bad without exploring it with patients and determining how it affects

their dying experience. To accomplish that, professionals must be insightful about their own spiritual views and comfortable talking with patients about uncertainty, spirituality, and dying. For some, that might require a deep, personal reflection about spirituality and dying; whereas for others, it requires finding an avenue to approach patients about sensitive topics. For instance, one way to approach sensitive topics is to tell patients that many individuals have questions about dying that they need to explore and that the nurse would be willing to listen to them or provide them with other resources.

Health professionals also can pay close attention to the natural conversations of their patients and recognize that comments about meaning, relationships, beliefs, self-transcendence, and values have strong spiritual connotations that may indicate spiritual uncertainty. Understanding the reciprocal relationship between uncertainty and spirituality will help healthcare providers to anticipate changes in intensity or direction. Through these efforts, health professionals can improve their relationships with patients, demonstrate their willingness to be present with them, and help them to process their spiritual uncertainties.

## Future Research

This article underpins the necessity for additional research to further examine the role of spiritual uncertainty in the dying experience. Spiritual uncertainty offers a novel understanding of spirituality at the EOL. Additional research is needed to address these gaps, which include but are not limited to (a) the development of a typology of the sources of spiritual uncertainty; (b) an explanation of how each source is experienced, including the quality and ranking as to which the source of uncertainty is problematic; (c) the resources needed to manage those sources considered problematic; and (d) the development of clinical tools that can quickly assess spiritual uncertainty among patients nearing the EOL. Additional research also should focus on the uncertainties that health professionals and family members have and how their uncertainties affect the dying patient. That information should lead to interventional studies that will directly improve the experience of those who are dying.

## Conclusion

The current article presents an innovative way of viewing how spirituality may be experienced at the EOL. The possibility that uncertainty and spirituality can coexist as simultaneous and even blended experiences at the EOL is supported and warrants additional exploration. Developing a better understanding of spiritual uncertainty will enhance how health professionals provide spiritual care, improving EOL care.

### Knowledge Translation

Uncertainty represents a unique way that patients who are terminally ill can experience spirituality but has received little attention in the literature.

Health professionals may discuss spiritual uncertainty with patients to facilitate spiritual and end-of-life care.

This discussion supports the possibility that spirituality and uncertainty can exist simultaneously for people nearing the end of life.

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