

# 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