
“All my saints are within me”: Expressions of end-of-life spirituality

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ABSTRACT

Objective: With spirituality being one of the most important components of end-of-life (EOL) care, this study explored the oral responses of 44 dying persons who expressed spirituality.

Method: Four identified spiritual themes: religious systems of beliefs and values, life meaning, purpose and connections with others, nonreligious systems of beliefs and values, and metaphysical or transcendental phenomena served as a framework for a content analysis of 91 spiritual references.

Results: From the content analysis, eight interrelated and separate themes emerged. Although the highest number of responses centered on religious beliefs and values, nonreligious beliefs and values that included reason, dignity, mental discipline, and communion were expressed. The themes of life meaning, purpose, and connections with others also surfaced as important aspects of EOL spirituality.

Significance of results: The findings support the need for hospice/palliative care professionals to approach spirituality from other than a Judeo-Christian viewpoint, help dying persons create meaning and purpose within the context of their lives, and assist them in their desire for connectedness to faith communities and other significant individuals in their lives.

KEYWORDS: Spirituality, Hospice, Palliative Care, Death and dying, End of life

INTRODUCTION

The importance of spirituality in reducing end-of-life (EOL) despair and improving psychological well-being in dying persons is well supported (McClain et al., 2003; McClain-Jacobson et al., 2004). McClain-Jacobson et al. reported that spirituality induced comfort, offered protection, and improved quality of life for individuals with advanced cancer (Tarakeshwar et al., 2006). Conversely, persons who approached death with less spiritual well-being had more despair (Chibnall et al., 2002), depression, and anxiety (Delgado-Guay et al., 2011). Given that dying individuals are prone to spiritual distress or the “pain caused by extinction of the being and meaning of the self” (Murata, 2003,

p. 17), researchers continue to search the link between spirituality and psychological well-being in EOL populations. With spirituality a much broader concept than religion (Sinclair et al., 2006), and with “spiritual work fertile ground for further investigation” (Williams, 2006, p. 407), conceptual meaning of spirituality and its influence on EOL care warrants further clarification.

In their review of research on spirituality in EOL populations, Sinclair et al. (2006, p. 475) noted that it focused primarily on the individual, and they concluded that there was still “little insight into the spiritual experiences” of dying persons. Whereas previous efforts defined spirituality (Mahoney & Graci, 1999; Meraviglia, 1999; Tanyi, 2002; Chiu et al., 2004), and attested to its “existential, relational, transcendent, subjective, and expressive” (Chiu et al., 2004, p. 424) components, a recent review concluded that “spirituality refers to those beliefs,

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values, and practices that relate to the search for meaning, purpose, or transcendence, which may or may not include belief in a higher power" (Selman et al., 2011, p. 730). Hence, for individuals who face terminal illness, existential issues, such as the meaning and purpose of one's existence and other spiritual beliefs, may come to the forefront in EOL situations.

Faced with "no greater existential crisis than that of facing one's own death" (Breitbart et al., 2004, p. 370), the existential part of spirituality served to protect the psychic (Laubmeier et al., 2004). Therefore, when faced with suffering, dying individuals drew inward and diminished spiritual distress by finding life's meaning (Hall, 1998; Herman, 2001), and by creating purpose (Mahoney & Graci, 1999). The existential dimension also helped dying persons transcend their dire situations and overcome the circumstances of terminal illness (Thomas & Retsas, 1999).

In their attempt to define spirituality's "intricate, enigmatic, abstract and ambiguous" meanings, Sessanna et al. (2007, p. 252) reviewed 73 nursing and health-related references. Their review identified four main themes: 1) spirituality as religious systems of beliefs and values; 2) spirituality as life meaning, purpose, and connection with others; 3) spirituality as nonreligious systems of beliefs and values; and 4) spirituality as metaphysical or transcendental phenomena (p. 255). These same reviewers concluded that a definition of spirituality should include all four themes.

In further explanation, Sessanna et al. (2007) defined the first theme as "affiliation with a religious or faith community." The second theme described "connection to others and connection to something greater than oneself" (p. 256). Through connectedness, individuals find meaning and purpose and form meaningful relationships. The third theme noted that spirituality is not always defined by formal traditions or religious affiliations, but may be expressed through art, nature, or a means of expressing life's meaning and purpose. The final theme found a state of expanded consciousness, whereby individuals move beyond physical limitations to transcend or rise "above life in an abstract sense" (p. 257). Sessanna et al. concluded that these spiritual themes are impacted by both innate or intrapersonal attributes, and extrinsic or external properties, such as religious communities. In another review of 71 research studies on EOL spirituality and subsequent concept analysis 11 themes emerged (Vachon et al., 2009). Along with the four themes found by Sessanna et al. (2007), Vachon et al. added dimensions of hope, attitude toward death, spirituality as developmental in nature, appreciation of life, and having a conscious aspect, along with transcendence. Transcendence

was further separated into two categories: 1) the self, and 2) a Higher Being. With these added components, Vachon et al. defined spirituality as a "developmental and conscious process, characterized by two movements of transcendence: either deep within the self or beyond the self" (p. 56). They also reported that further research is needed to support the developmental aspect of spirituality, and to affirm the existence of the two levels of transcendence (self and a Higher Being).

Given that Vachon et al.'s (2009) review did not include a category of nonreligious systems of beliefs, the less complex four-dimensional model identified by Sessanna et al. (2007) was used as the framework to guide this study. With no studies having been found that categorized the responses of expressed spirituality by dying persons according to these four themes, the purpose of this study was to determine the fit of home hospice patients' referenced spiritual expressions within these themes. The specific questions that guided this study were the following: 1) What religious beliefs and values do dying persons express? 2) How are life meaning, purpose, and connectedness to others expressed by dying individuals? 3) What nonreligious values and beliefs come forth in the responses of dying persons? And 4) In what ways are metaphysical or transcendental experiences reflected by dying individuals?

METHOD

Sample

The present study is a secondary analysis of oral responses that were collected in an initial triangulated study of 97 home hospice patients. As required for any secondary analysis, the Human Subjects Division of the sponsoring institution gave their approval. The inclusion criteria for the initial study were as follows: ≥ 30 years of age, English speaking, intact cognitive function, and signed hospice consent with diagnosis of ≤ 6 months to live. Whereas other variables that did not include spirituality were researched in the original combined quantitative and qualitative studies, references to spirituality emerged in the responses of 44 dying persons. In responding to items on tools that measured pain, social support, physical function, and psychological adaptation in the face-to-face testing sessions, 44 of the 97 participants openly talked about their spirituality and expressed spiritual aspects. Particularly, questions on the Life Closure Scale, with its domains of finding meaning and maintaining self-integrity (Dobratz, 1990, 2004) drew frequent responses. As listed in the demographics in Table 1, the mean age of the 44 participants who expressed spirituality was

Table 1. Demographics of the participants

Demographics (44 participants)	Number	Percent
Mean Age	66.1	
Gender (female)	17	38.6
Gender (male)	27	61.4
Ethnicity (Caucasian)	38	86.4
Mexican-American	4	9.1
African-American	2	4.5
Diagnoses (Cancer)	35	79.6
HIV/AIDS	4	9.1
ALS	2	4.5
Other	3	6.8
Religious affiliation		
Protestant	26	59.0
Roman Catholic	12	27.3
Jewish	1	2.0
Other	5	11.7

66.1 years, with a larger sample of men (61.4%) than women (38.6%). Their diagnoses were cancer (79.6%), AIDS (9.1%), amyotrophic lateral sclerosis (ALS) (4.5%), and end-stage cardiac disease (6.8%). The ethnicity of the participants was 86.4% Caucasian, 9.1% Mexican-American, and 4.5% African-American. The religious affiliations for the participants were 59.0% Protestants, 27.3% Catholic, 2.0% Jewish, and 11.7% other unidentified denominations. The participants were all home hospice patients and their oral responses were collected in various home settings, which included single homes, apartments, mobile homes, and a residence hotel.

Design

The study's design was a content analysis of the oral responses of 44 dying persons who referenced spirituality framed within Sessanna et al.'s (2007) model. Even though the present study involved a secondary analysis of oral responses, data can be interpreted in different ways "to fit the purposes of the project for which they are put to use" (Sandelowski, 2011, p. 347). Whereas the same data are used, they are focused on a different aim and another meaning is construed; therefore, they serve as a new data set (Sandelowski, 2011). In analyzing the data for a different purpose, the verbatim content that referenced spirituality was extracted and the coding schemata centered on the four themes that were identified in Sessanna et al.'s (2007) concept analysis: religious systems of beliefs and values; life meaning, purpose and connections with others; nonreligious systems of beliefs and values; and metaphysical or transcendental phenomena. A more in-depth description of these themes appears in the Introduction.

During the coding process, it became apparent that the content of the participants' responses did not neatly fit within the four themes, that some of the themes were interconnected, and that they formed eight, rather than four, themes. The frequency of responses and overall percentages for each of these eight categorical themes are reported in the Results section that follows.

RESULTS

The results of this content analysis of the oral responses of dying persons found that the 44 participants referenced spirituality a total of 91 times. As listed in Table 2, three separate themes (religious systems of beliefs and values, nonreligious systems of beliefs and values, and transcendence), two distinct parts of the second theme (life meaning and purpose, and connection), and three interrelated themes emerged from the analysis. The frequencies and percentages of these eight separate and connected spiritual themes are described in order from the highest to the lowest ranking.

The highest number of oral responses (30.8%, $n = 28$) expressed spirituality as a system of religious beliefs and values. The second highest number of responses (23%, $n = 21$) related spiritual beliefs and values to connectedness. Next, 16.5% ($n = 15$) were expressions of how spiritual beliefs and values helped these dying participants make sense of their illness and create meaning. In their order of descending frequency, 11% ($n = 10$) referenced nonreligious systems of beliefs and values, and 8.8% ($n = 8$) expressed life meaning and purpose that was not connected to any of the other themes. Whereas 4.4% ($n = 4$) of individuals referenced connection to others, religious systems of beliefs and values were linked to transcendence by 3.3% ($n = 3$) participants,

Table 2. Spirituality themes, frequency of responses, and percentages

Theme	Number of responses	Percentage
Religious beliefs/values	28	30.8
Religious beliefs/values/ connections	21	23.0
Religious beliefs/values/life meaning/purpose	15	16.5
Nonreligious beliefs/values	10	11.0
Life meaning/purpose	8	8.8
Connections	4	4.4
Religious beliefs/values/ transcendence	3	3.3
Transcendence	2	2.2
Total	91	100%

and only 2.7% ($n = 2$) of the respondents expressed transcendence. From the highest to the lowest number of responses and as depicted in Table 2, the narrative descriptions for each of these eight spiritual themes follow.

Narrative Descriptions

Religious Systems of Beliefs and Values

As described in the highest number of oral responses, participants expressed their religious beliefs and values. One participant responded with these statements, "I can't imagine how scared you would be without God to believe in. I know where I'm going. Without Him (God) I don't know what I'd do." Still another replied, "You accept the Lord bring. I believe in Him as my Lord and Savior. When my time comes, I'm going to another place." One more participant said, "I'm not afraid to die. When I leave here, I'm going to be with Jesus Christ." A person of the Mormon faith remarked, "I'm looking forward to the spirit world." This individual who had a diagnosis of ALS also said in reference to his dying, "I get to leave this dried up body and dance around with the spirits." Also in reference to his Mormon faith this person remarked, "We believe that the body is a necessity and that the body and spirit come back together again at the resurrection." And yet another replied, "I was brought up a Catholic and I do believe in God and a Higher Power." Another dying person remarked, "My faith is within me. I'll just believe in God and that will do." In reference to her faith, a woman said, "Our faith is what keeps us going, and we believe that God is always there." In summary, the respondents who discussed this theme spoke about the comfort and solace that their personal religious beliefs and values afforded them. Moreover, as described, their belief in an afterlife and changed bodily form diminished their fear of dying.

Religious Systems of Beliefs and Values as Connection

The second highest number of responses connected these two spiritual themes. A dying woman said, "I pray everyday for God to help me. He has angels that take care of us." Another woman expressed that she never felt alone and remarked, "God is with me and you can't be alone." Still another person replied, "If I feel like talking, I talk to God. All my saints are within me." Another man said, "I belong to a Bible study group. I can't go now, but a couple of people come here." Still another man replied, "God is where I get my security, the people who come to see me don't give me that secure feeling." As said by yet another dying individual, "First of

all, God is the most important person in my life." One woman remarked, "We belong to a little Baptist church and they're just like family." To summarize this theme, these dying individuals expressed the importance of their religious beliefs and values as a means of communion with God and other individuals within their faith communities.

Religious Systems of Beliefs and Values, Life-Meaning, and Purpose

As noted by the third highest number of oral responses, the first theme was related to life meaning and purpose. One woman who was at the end of her life remarked, "God put me here for a purpose. I believe that prayer of St. Francis Assisi—to change what you can and accept what you can't." Another person said, "God put you here and everything was planned. There's a Higher Power." In referring to a reason for their illness, it was said, "God has a reason for everything," "I think these things happen to you for a reason," and "God put you here and whatever happens, happens for a reason." One man replied, "It gets down to God's will. I was able to accept God's will in that He gives us to ability to 'stand what we don't understand.'" A woman remarked, "I don't know how people make it without faith. Without faith, nothing makes sense," and another woman said, "God wanted me to go through this now while my husband is able to take care of me."

The responses of the dying individuals that related to this theme described how their faith in God helped them accept their illness as part of an ordained Divine plan that was beyond their comprehension and reason.

Nonreligious Systems of Beliefs and Values

The next highest number of responses supported nonreligious systems of beliefs and values as a separate, unrelated theme. As said by one dying person, "I've never been a real religious person, but I'm spiritual." Another woman noted, "We're here to develop reason. We have to work to develop reason. I feel like I've been building all my life to come through this." One man spoke about his value of mental discipline by responding, "I feel that I've had excellent mental discipline all my life. If you don't allow yourself to dwell on things, you find you have a lot of strength." Another spoke of dignity, "I've tried to carry this through with as much dignity as possible. That's the way I've tried to live." One woman replied, "We don't really go to Church. My mother taught me that all religions are a branch of a tree and that all roads to God are good." Yet another man responded by saying, "I'm not afraid of dying, I believe in reincarnation." One woman said, "I think of good things

like mountains and the ocean.” Two men spoke about Alcoholics Anonymous (AA) by stating, “I wouldn’t have made it without AA,” and “I have the fellowship of AA and I do what I’m encouraged to do.” Although not linked to formal religious institutions or dogmas, the dying persons who expressed nonreligious spirituality found solace in communing with nature, maintaining mental discipline and reason, upholding their dignity, embracing all faiths, and keeping fellowship with an inclusive organization.

Life Meaning and Purpose

The responses that were given by dying persons spoke about how their illness helped them find meaning and purpose in life. It was remarked, “Things happen for a reason. I was put here for a purpose.” One man said, “I’m better off compared to others.” Whereas another said, “I think a lot of good has come from my being sick” and yet another remarked, “I think there’s always someone worse off than you. My problems are little compared to others.” Unlike the theme in which individuals found meaning and purpose through their belief in a Divine Power, these respondents created life-meaning and purpose through their own individual efforts.

Connection to Others

Although there were a small number of responses in this category, the importance of being connected to others was noted. One man said, “I do believe that I wouldn’t have made the effort to live if my wife hadn’t been around.” Another noted, “I’m really lucky, people always want to come over. Sometimes it gets to be too much.” A woman said, “My friends have given extra for me. I think you have to give to receive. I’m continually grateful for their love and support.” Yet another woman remarked, “My neighbor and friend came yesterday. I couldn’t say much, but she just held my hand. That was just wonderful.” Through connectedness to others, these dying persons spoke about the meaningful relationships in their lives that helped and sustained them. The touch given by a friend, the loyalty of a spouse, and the love and support of others were acknowledged.

Religious Systems of Beliefs and Values and Transcendence

There were few responses in this interconnected theme, but these dying persons talked about being able to relinquish their physical suffering to a Higher Power. As said, “I’ve turned things over to God and I’m ready to go. When He say’s He’s ready, I’m ready.” Another woman remarked, “I had a turnaround last week. I turned things over to God and I feel tremendous relief.” Through their belief in God, these

individuals expressed their ability to rise above or transcend their physical self.

Transcendence

Although there were only two responses that fit with this theme, one man spoke of the mental effort that he made to put his illness and impending death out of his mind. He replied that he then, “Turned boredom into peacefulness.” Another individual spoke of the immense mental concentration that he used to rise above the physical constraints of his illness. He stated, “I saw a red light in my mind and I remember thinking, if I let it get too strong, then I’m gone. I put it out of my mind and made a mental effort to do it. I’ve always been a strong person mentally.” Unlike the individuals discussing the previous theme who transcended their illness by giving their suffering over to God, these individuals relied on their own efforts to rise above their difficult situations.

DISCUSSION

Although the largest number of responses was in the first theme of religious systems, beliefs and values, the interconnectedness of this theme to the other themes was an unexpected finding. The first theme of religious systems of beliefs and values was also linked to components of the second theme (finding meaning, purpose, and connections to others), and to transcendence by way of a Higher Power (fourth theme). The third theme of nonreligious beliefs and values showed clear thematic boundaries that did not overlap with, or connect to, any of the other themes. The spiritual theme of finding meaning and purpose was related to religious beliefs and values, but it was also a separate category and distinct from “connections to others.” The interrelationship of the themes was supported in Sessanna et al.’s (2007) initial systematic review when they concluded that spirituality definitions were intertwined and did “not neatly fall within themes” (p. 254). Nonetheless, these dying participants most often mentioned their religious beliefs and values.

There were multiple responses from dying persons that spoke of a belief in an afterlife, or of their continuing onward after their life on earth had ended. These dying persons talked about looking forward to a better place or going to the “spirit world” as defined by their systems of religious beliefs and values. In reference to an afterlife, they looked forward to a “recovery of the future, others, and autonomy beyond death” (Murata, 2003, p. 19). They also spoke of the importance of religious symbols and practices, such as communion, baptism, last rites, and prayer.

As recorded in the frequency of responses, the next expressed spiritual theme was an internal

connection to a Higher Being or Power, and/or an external connectedness to faith groups and communities. Murata (2003) reported that when individuals face a life event, such as death, “they rediscover their relationships with others and ‘God,’ through exploration of the inner self” (p. 16). First, the connectedness that dying persons felt to a Higher Power was noted by their not feeling alone, asking for help, feeling secure, and talking with God. Persons with higher levels of spirituality/religiosity who sought spiritual support from God were found to have improved psychological well-being (Kudel et al., 2011). Whereas the lack of religious rites and services has been identified as an unmet need in home hospice patients (Hampton et al., 2007), these participants spoke about being the recipients of spiritual-based readings, prayers, and songs from members of their faith-based communities. The need of advanced cancer patients to be connected to their spiritual/religious communities was reported (Alcorn et al., 2010), and the importance of a communal approach to spirituality was noted by Sinclair et al. (2006).

The next highest number of responses comprised a theme that linked religious beliefs and values with life meaning and purpose. The existential component of spirituality, particularly, which is “finding meaning and purpose in one’s life” (p. 48) was associated with less psychological distress in cancer patients (Laubmeir et al., 2004). As recorded by the frequency of responses surrounding meaning and purpose, spiritual meaning “may become increasingly important to patients at the end of life” (Balboni et al., 2007, p. 558). The importance of this categorical theme was also noted by Vachon et al. (2011) who found that meaning and purpose was a predominant theme. In fact, Vachon et al. concluded that spirituality could even be defined as “a search for meaning and purpose in life or as a feeling to have found a meaning and purpose in life and death” (p. 55). The number of responses that linked religious beliefs and values to these concepts, as well as the references that were not linked to religious beliefs and values lend support to Vachon et al.’s conclusion.

The categorical theme of nonreligious beliefs and values that emerged was confirmed, in that spirituality is not always associated with religious affiliations (Herman, 2001; Tanyi, 2002). The participants’ references to different philosophical beliefs and spiritual values of reason, mental discipline, dignity, reincarnation, and communion with nature point to the fact that dying persons approach spirituality from a myriad perspectives. The importance of dignity as a predominant concept during the dying process is well supported in the palliative care literature (Chochinov et al., 2002; Chochinov, 2004). Although the demographics of the participants revealed that

they, for the most part, were Caucasian representing a Judeo-Christian viewpoint, the increasing diversity of the United States population reflects professionals’ need to understand spiritual expressions from other cultural approaches (Sinclair et al., 2006). The recent systematic review by Selman et al. (2011) supported this requisite in their emphasis that spirituality is both “embedded in culture” (p. 729) and “expressed through culture” (Bryson, 2004, p. 323). Therefore, although categorized in this study as a nonreligious belief and value, depending upon the influences, reincarnation could either be a religious belief or a cultural value.

When the transcendental theme was defined as “transcending or rising above life in an abstract sense” (Sessanna et al., 2007, p. 257), there were only a few references to support that individuals had reached this state. The lack of clarity on the conceptual definition makes this a difficult theme to categorize. From being defined as being in relationship with “something greater than oneself” (Bryson, 2004, p. 323) and “feeling of connection and mutuality with a Higher Power” (Vachon et al., 2009, p. 56), to “expanding one’s conceptual boundaries inwardly through introspective activities, outwardly through concerns about others’ welfare, and temporally by integrating perceptions of one’s past and future to enhance the present” (Reed, 1991, p. 5), transcendence could be a state of prayerfulness or mental ascension above one’s physical body. For the purposes of this analysis, transcendence was viewed as relinquishing one’s physical life and embracing approaching death (Dobratz, 2002–2003). Although a larger number of responses are needed to support this theme, Vachon et al.’s (2011) two-dimensional framework that identified transcendence by way of self and a Higher Power could be emergent. As noted in the responses by these few individuals, they were able to rise above their situations by connecting to God or a Higher Power, whereas others used sheer mental efforts to rise above their dire situations. Nevertheless, the lines between transcendence and connectedness are blurred, and further research is needed to clarify conceptual meanings.

Clinical Implications and Limitations

Although the number of responses in the categorical theme of nonreligious beliefs and values was small, religious beliefs and values alone do not capture the true meaning attributed to the complex, multifaceted construct called “spirituality” (Puchalski et al., 2003); therefore, professionals need to explore nonreligious spiritual meanings for dying individuals. Furthermore, given the large number of responses that addressed life meaning and purpose, the important

role that the existential components of spirituality play in helping dying persons create meaning out of the context of their lives is well supported. Hence, interventions that increase or maintain this core component of spirituality are paramount in palliative care (Breitbart et al., 2004). Most importantly, dying persons can do their best spiritual work when they are affirmed and valued by palliative care professionals who understand the importance of spiritual care (Grant et al., 2004).

Because of the small sample sizes in some of the categorical themes, other than the fact that these dying persons appeared eager to express their spiritual beliefs and values, searched to find meaning and purpose in their presence on earth, and desired to maintain connectedness with others, it is difficult to draw conclusions about EOL spirituality with these participants. A larger sample of participants from more culturally diverse backgrounds would add to our understanding of nonreligious beliefs and values and transcendence in life's final transition. With a goal to "capture the patient's world without interpretive bias" (Bryson, 2004, p.327), the need for further research that clarifies our understanding of spiritual dimensions in death and dying continues to be warranted.

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