

Challenges in Assessing Spiritual Distress in Survivors of Cancer

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Background: Many efforts have been made to better integrate spiritual assessment into the care of patients with cancer, with varying degrees of success in different parts of the United States. Little work has been done to describe challenges that face those who seek to implement assessment in busy ambulatory settings, particularly in the northeastern section of the United States.

Objectives: This study sought to test the feasibility of a screening process describing spirituality, distress, and spiritual transformation in cancer survivors after chemotherapy for lung or gastrointestinal cancer.

Methods: This descriptive pilot study took place in a rural National Cancer Institute–designated comprehensive cancer center, referral center, and outpatient medical oncology clinic. A web-based questionnaire was completed by 29 survivors, and 22 declined participation.

Findings: Respondents were primarily Christian, aged 60 years or older, and an average of 18 months post-diagnosis. The mean spiritual distress score was 1.38 (SD = 2.09), and the mean psychological distress score was 3.03 (SD = 2.73). Participants reported mean spiritual well-being, positive degree of spiritual growth, and little spiritual decline. The opportunity for spiritual growth among survivors creates a need for effective assessment and intervention to promote spiritual growth and mitigate spiritual decline and spiritual distress.

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New accreditation standards from the American College of Surgeons (2012) Commission on Cancer mandate that referrals for assessment and management of distress be considered part of patient care by 2015 (ASCO Post, 2013). Evidence-based literature on distress related to spirituality in cancer survivors is sparse because of methodologic challenges for researchers; however, the literature base is growing (Pearce, Coan, Herndon, Koenig, & Abernethy, 2012; Peteet & Balboni, 2013). Consequently, spiritual distress is often overlooked, particularly among outpatients, despite patients' desire to have spirituality addressed (McCord et al., 2004; Phelps et al., 2012). In addition, a significant lack of research exists on the role that regional geography plays in patients' spirituality within this context.

Clinical assessments of spirituality are generally limited to a single religious preference question, and current research tools are often too lengthy to be clinically useful in busy outpa-

tient clinics for patients receiving survivorship care. No rapid, clinically useful standardized screening and referral process for spiritual distress has been implemented in this setting. Therefore, this pilot project aimed to determine the feasibility of a process for assessing spirituality in a medical oncology outpatient setting in northern New England in the United States using an online questionnaire for patients with lung or gastrointestinal (GI) malignancies. The authors also investigated whether patients could discriminate spiritual distress from global psychological distress.

Background

Spirituality has been defined as the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to the self, to others, to nature, and to the

significant or sacred (Puchalski et al., 2009). *Distress* has been defined as a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common, normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crises (National Comprehensive Cancer Network [NCCN], 2012). Distress in cancer survivors may arise out of a variety of psychosocial factors (Holland, 2000) and cause emotional distress, but common existential questions persist (Miller, 2005): Why did this happen to me? What is the meaning of my life? What happens when we die? These existential questions belong in the realm of spiritual distress. *Spiritual distress* or *spiritual suffering* can be described as a state in which a person is unable to fulfill basic human needs for love, hope, purpose, and connection with others, or a situation in which conflict exists between an individual's core beliefs and their personal experience (Bartel, 2004). Exploring answers to existential questions can profoundly affect spirituality in survivors and can be transforming or lead to a spiritual crisis (Peteet & Balboni, 2013) that causes distress. Spiritual transformation can be positive (toward spiritual growth) or negative (toward spiritual distress). Spiritual transformation via spiritual growth is one way to describe how people diagnosed with cancer react to their diagnoses to make meaning and find purpose.

Spiritual growth has been described qualitatively (Denney, Aten, & Leavell, 2011) as a sense of increased connection to God (or a higher power), resulting in a belief that God is in control of life events. Patients found themselves more interested and engaged to discover what higher purpose their cancer experience served. They discovered that giving over control of their cancer experience helped to decrease psychological and emotional stress. Of note, participants reported that increased spiritual support from family and friends led to increased spiritual growth. Positive changes were reported in using faith to cope and in a greater sense of divine peace and serenity. Spiritual growth after a cancer diagnosis has been associated with better adjustment in survivors (Carver & Antoni, 2004), indicating a need to focus on negative aspects of spirituality early in the cancer experience to develop and maintain positive coping (Gall, Charbonneau, & Florack, 2011).

In contrast, the practicality of spiritual assessment is a major challenge, particularly in the outpatient setting. Lack of provider training in spiritual care (Balboni et al., 2013), standard psychometrically tested tools, and standard methods are barriers to assessing spirituality. Most tools are lengthy, rendering them impractical in busy clinic settings. Some clinical assessments of spirituality, such as the Faith, Importance and Influence, Community, Address or Application (FICA) tool (Puchalski & Romer, 2000) have been validated (Borneman, Ferrell, & Puchalski, 2010). HOPE (H representing sources of hope, strength, comfort, meaning, peace, love, and connection; O representing the role of organized religion for the patient; P representing personal spirituality and practices; and E representing effects on medical care and end-of-life decisions) (Anandarajah & Hight, 2001) is clinically useful but lacks psychometric testing as

well as standardization and efficiency in administration. Taylor (2003, 2006) has developed and tested the Spiritual Interests Related to Illness Tool (SPIRIT), but it is untested in the medical oncology setting. Notable efforts have been made toward assessment in ethnically diverse populations (Hamilton, Crandell, Carter, & Lynn, 2010), but those efforts address a limited piece of spirituality, such as cultural beliefs and practices.

Assessment is further challenged by the concept of regional differences in spirituality, a topic virtually nonexistent in healthcare literature. Regions of religion have been identified classically (Shortridge, 1977) in the United States and are supported by Pew Forum on Religious and Public Life (2008) survey results; however, current work regarding regional variation is severely lacking. In the Pew Forum on Religious and Public Life (2008) survey, New Hampshire and Vermont results were combined, and the combined rankings were in the lowest category nationally for specific belief in God (54% versus 71%), importance of religion in life (36% versus 56%), and frequency of daily prayer (43% versus 58%). In addition, one of four U.S. citizens reported that they were unaffiliated with a faith tradition, with men and younger people more likely to be unaffiliated.

Four dimensions of religion can be identified and reliably used to create a regional picture of American religion in northern New England: a traditional Catholic-Protestant division, contrast between liberal and conservative Protestantism, the level of religious intensity or commitment, and the degree of religious diversity (Shortridge, 1977). New England's religious and cultural background, with respect to a large urban Roman Catholic presence and staunch rural Mainline Protestant, shaped the region into historically competitive groups that vied for political and social control until World War II (Walsh & Silk, 2004). Therefore, religion in the region is viewed as a potentially strongly divisive force. Religion in New England "is therefore often addressed obliquely or not at all" (Walsh & Silk, 2004, p. 13). The reluctance to talk about faith beliefs is supported by a study out of the University of Vermont, which demonstrated much lower willingness for spiritual interaction (only 50% in a near-death scenario) with healthcare providers than national statistics would predict (Maclean et al., 2003). New England's unique rural demographic area, with respect to religion and spirituality, poses a research challenge. Therefore, this descriptive pilot study described spirituality, spiritual transformation, and psychological and spiritual distress at the Norris Cotton Cancer Center (NCCC) at Dartmouth Hitchcock Medical Center, a National Cancer Institute–designated comprehensive cancer center and regional referral center for New Hampshire, Vermont, and parts of Maine and Massachusetts. NCCC serves a primarily rural population.

Methods

Patients were systematically and sequentially recruited at their appointments to form a convenience sample of 60 medical oncology outpatients older than age 18 years, and 30 of the participants were female. Half of the participants had colon cancer, and half had lung cancer. Stage IV survivors of cancer were excluded because the complex issues of spirituality in end-of-life care were outside the scope of this study. Variables

chosen for the study were spirituality, spiritual transformation, distress, and select demographic variables including diagnosis, age, gender, ethnicity, level of education, income, insurance, children living at home, religious affiliation (11 choices given), and months since diagnosis.

After successful review by the Committee for the Protection of Human Subjects, data were collected during 18 months in the outpatient medical oncology clinic. All English-speaking patients with lung (non-small cell and small cell) or GI cancer older than age 18 with stage I, II, or III disease were eligible. Patients received a laptop computer with information and instructions, informed consent, option not to participate, and reasons why they may not want to participate appearing on the first screen. The number and reasons for patient refusals were recorded.

Questions appeared one at a time on the computer screen; 49 questions used the three research tools in total, and there were 10 demographic questions. Subjective questions were answered using Likert-type scales. Example questions include, "To what extent has your illness made positive changes in your life?" and, "Do you sense a purpose/mission for your life or a reason for being alive?" Participants also were asked to rate how true statements were. Statements included, "Spirituality has become more important to me," and, "My relationships with other people have taken on more spiritual meaning." Demographic questions included diagnosis, age, gender, ethnicity, level of education, income, insurance status, marital status, children and parents living at home, religious affiliation, and months since diagnosis. Time to completion was about 10–15 minutes. If a patient wished to participate but was unable to use the laptop, the researcher read the questions and entered the answers into the computer. Paper copies were not offered. Completion of the tool by the patient directly or indirectly constituted informed consent.

Spiritual well-being was measured by the seven-item spiritual well-being subscale of the Quality of Life–Cancer Survivors instrument, which has been tested as valid and reliable (Ferrell, Dow, & Grant, 1995). The subscale uses a 0–10 Likert-type scale and measures importance of religious and spiritual activities, uncertainty, purpose, and hope.

The 40-item Spiritual Transformation Scale measures transformation as a function of spiritual growth and spiritual decline across the domains of worldview, goals and priorities, sense of self, and relationships. The instrument uses a 1–7 Likert-type scale and is psychometrically sound (Cole, Hopkins, Tisak, Steel, & Carr, 2008), with scores of spiritual growth predicting better psychological and spiritual well-being following a diagnosis of cancer and scores of spiritual decline predicting poorer well-being.

Psychosocial distress was measured by the NCCN Distress Thermometer, a valid and reliable tool (Holland, Jacobsen, & Riba, 2001; Patrick-Miller, Broccoli, Much, & Levine, 2004). Two thermometers were used; one asked the participant to rate psychological and emotional distress, and the other asked the participant to rate spiritual distress. A numeric score was identified to answer the question.

Analysis

Initial analysis determined summary statistics for patient characteristics. Distributions were examined for the scales and

correlations were estimated among variables. Spiritual need was summarized as a categorical variable with counts and proportions in each category. A multiple logistic regression determined associations between spiritual need and covariates. SAS[®], version 9.2, was used to conduct the statistical analyses. Sample size calculations were conducted to ensure that there were adequate numbers of participants to detect clinical significance for the key outcome variables of spiritual well-being, spiritual transformation, or spiritual distress using a sample size of 60.

Results

Twenty-nine patients completed the questionnaire (see Table 1). Because of the high rate of people who declined participation, the study was stopped prior to reaching the accrual goal of 60 patients. Twenty-two participants declined to participate for various recorded reasons and are reported from standard options or free text (see Table 2). The mean age of respondents was 60 years, and mean time from diagnosis was 28 months. Most reported a Christian faith tradition ($n = 24$) and were Caucasian, middle class, and married. All had health insurance. Average time from diagnosis was about two years. The mean

TABLE 1. Descriptive Characteristics (N = 29)

Characteristic or Instrument	\bar{X}	SD
Age (years)	60.9	9.34
Months since diagnosis	27.83	31.76
Spiritual well-being subscale ^a	39.24	15.68
Spiritual Distress Scale	1.38	2.09
Distress Thermometer	3.03	2.74
Spiritual Transformation Scale		
Spiritual growth	3.95	1.61
Spiritual decline	0.68	0.39
Characteristic	n ^b	
Male	16	
Caucasian	28	
Insured	29	
Annual income (\$)		
Less than 20,000	4	
20,000–74,999	17	
75,000 or greater	8	
Living with children or parents at home	11	
Religion		
Christian	24	
None	3	
Other	2	
Marital status		
Never married	2	
Married, living with partner, or civil union	21	
Separated or divorced	3	
Widowed	3	
Cancer type		
Lung	15	
Colon	9	
Pancreatic	4	
Liver	2	

^a From Quality of Life–Cancer Survivors instrument

^b Missing values were excluded from analysis.

spiritual well-being score was 39 (range = 0–70). The mean spiritual growth score was 3.95, and the mean spiritual decline score was 0.68. Diagnoses of lung and GI cancers were equally proportional. The population as a group reported a relatively average level of spiritual well-being, some positive degree of spiritual growth, and little spiritual decline.

Discussion

Several aspects of this pilot project demonstrated a need to include spiritual distress within the context of distress management. Assessment of spirituality was feasible in the outpatient setting; however, given the high refusal rate, further work needs to be done to determine why so many declined and to design a more optimal process. For those patients who completed the questionnaire, results of this pilot demonstrate a population that has experienced positive spiritual growth and minimal spiritual decline, with a moderate amount of psychological distress that they discriminated from a low level of spiritual distress.

After completing treatment and finding a new sense of normalcy, patients are faced with questions of meaning and purpose while they redefine their self-identity as cancer survivors (Rancour, 2008). It is critically important to address spirituality in survivors to facilitate the search for meaning, which supports coping and quality of life and minimizes spiritual distress from the cancer experience. The results of the spiritual well-being subscale in this study indicated that the group experienced a great deal of spiritual well-being. Spiritual well-being can have a direct clinical effect as demonstrated by evidence showing that spiritual beliefs can have an enormous impact on cancer treatment decisions (Silvestri, Knittig, Zoller, & Nietert, 2003). Results of the spiritual well-being subscale are consistent with the Spiritual Transformation Scale and spiritual decline scales. In this small pilot, the Spiritual Transformation Scale score for spiritual growth was higher (3.95 versus 3.76) and the spiritual decline score was lower (0.68 versus 1.46) than that reported by the creators of the tool in their mid-Atlantic United States popula-

tion (Cole et al., 2008). Patients were able to make a distinction between psychological distress (3.03), which was mild compared to spiritual distress (1.38), which was rated extremely low. Patients were able to do the questionnaires online with minimal assistance; however, several indicated they did not want to use computers. Patients who declined the questionnaires remain a significant problem; therefore, measuring spirituality, spiritual distress, and spiritual growth remains a challenge.

Identifying the nature of the challenge is the first step in determining a solution. The most significant limitation of this study also proved to be the most interesting result (Puchalski et al., 2009). Twenty-two of the 51 patients approached for the study declined to participate. This number was unexpected in this population given that patients were systematically and individually solicited. In contrast, only 0.8% refused to answer questions regarding their faith beliefs and affiliation in a national study and, of those, 92% reported a belief in God or a higher power (Pew Forum on Religious and Public Life, 2008).

These results led to the question of why the refusal rate was so high in this pilot population. Potential reasons are cited, but the results are strikingly consistent when considerations of regional variation in religiosity and culture are applied. Religion shapes and is shaped by regional culture (Walsh & Silk, 2004). The Pew survey found that the area in which the current study was conducted was relatively unreligious, which is a possible underlying answer for the lack of participation. This pilot population was older, with an average age of 60 years, and comprised of slightly more men than women. In New Hampshire and Vermont, 26% of citizens reported being unaffiliated, and 64% of people reported being Christian; nationally, 16% were unaffiliated, and 79% reported being Christian. This pilot more closely paralleled national statistics with respect to affiliation. The northeastern United States had the lowest level of religious diversity and the highest concentration of Catholics (Pew Forum on Religious and Public Life, 2008).

When the pilot population was compared with a population that is regionally more similar in secularity (la Cour, 2008), the results obtained in New Hampshire are quite consistent. Of note, the refusal rate was nearly identical (48%) to the present pilot population (43%). In addition, it can be suggested that this increased secular population of patients is being cared for by a similarly secular population of healthcare providers. This was demonstrated by a national study (Galek, Flannelly, Vane, & Galek, 2005) of palliative care physicians, nurses, social workers, and chaplains. The study found that, when compared regionally, those in New England scored themselves the lowest on religion and spirituality compared to the rest of the country. Significant provider discomfort may exist in this field among palliative care providers in countries, such as the United Kingdom (Abbas & Dein, 2011), with a history of palliative care much longer than in the United States. It would be difficult to expect secular patients who may be reluctant to discuss their religion or spirituality to communicate beliefs among secular providers. Therefore, it is reasonable to suggest that this population would be culturally less likely to participate in a study on the subject of spiritual distress but may be the population that most needs spiritual care.

The subject of spiritual distress leads to another point having to do with the limitations of using a questionnaire rather than an open-ended qualitative study. The difficulty inherent in using

TABLE 2. Reasons for Refusal (N = 22)

Reason	n
I do not want to answer questions about spirituality.	6
I do not have time.	4
I do not like computers.	3
No reason	3
I am too tired.	1
The questions will upset me.	–
Other ^a	5

^aOther reasons included, "I do not have any spiritual concerns," "I'm not having a problem, and I do not want to do it," "All of the above," "I do too many questionnaires already," and "If I were dying, I would want to talk about it, but we went for a cure, so I do not feel like I need to now."

Implications for Practice

- ▶ Find out what the general religion demographic for your region looks like.
- ▶ Ask survivors about their beliefs, values, and sense of meaning and purpose in life since their cancer diagnoses.
- ▶ Clarify language or terms patients use when they describe their spiritual beliefs.

questionnaires in research investigating religion was demonstrated in a group of nonresponders (Homan & Dandelion, 1997). Respondents identify ambiguity and inappropriateness and use it as an excuse to not answer, leading to serious concerns for semantics around religion. When patients do answer, there is a high degree of ownership of the answer, and the responses are quite personal. In this pilot, the title of the study investigating spiritual distress was printed at the top of the consent page of the online questionnaire. This term could be open to many interpretations. The operating problem in this pilot can be seen as what Homan and Dandelion (1997) discovered, that the major issue is the willingness of less semantically aware groups to agree to participate, and they settle for a categorization of their particular use of language and participate, potentially skewing the sample. In a personal communication (C. Hopkins, personal communication, October 15, 2012), the author of a similar study using the Spiritual Transformation Scale in Pennsylvania (Cole et al., 2008) noted an extremely low refusal rate, but the study title using the term *spiritual distress* was not used in that consent form. Therefore, the patients who declined participation in the current study may have been frustrated with or unaware of what the term meant and either consciously or unconsciously used it as an excuse not to participate.

Limitations

This pilot study is limited by the sample size and relatively low level of diversity in the rural northern New England region. However, it does highlight important sociologic issues that previously have gained little attention in the clinical study of spirituality in nursing literature. Although the limitations of the study preclude making generalizations beyond the study sample, close sociologic examination revealed potential explanations with respect to regional differences in spirituality and religion, as well as issues about language. Limitations in language point to a need for rigorous psychometric analysis of the tools currently in use.

Conclusion

The results suggest that it is feasible to assess spirituality using online tools in outpatient settings and suggests that survivors can discriminate psychological distress from spiritual distress. Limitations are consistent with a pilot design; however, challenges regarding regional variation in religion were uncovered in this study. Clearly, challenges in creating an assessment that is clinically useful, linguistically correct, and deemed useful by patients continue to plague the study of spirituality and

religion in the healthcare setting. However, this provides rich research opportunities.

Nurses should be aware of regional variations in religious beliefs and language to more accurately assess spiritual needs. Additional nursing research that includes sociologic perspectives and thorough psychometric testing of tools may minimize ambiguity around the semantics of spirituality and religion.

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