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Do spiritual patients want spiritual interventions?: A qualitative exploration of underserved cancer patients' perspectives on religion and spirituality

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ABSTRACT

Objective: This study examines religion and spirituality among advanced cancer patients from an underserved, ethnically-diverse population by exploring patient conceptualizations of religion and spirituality, the role of religion and spirituality in coping with cancer, and patient interest in spiritual support.

Method: Qualitative semi-structured interviews were conducted with patients who had participated in a study of a "mind-body" support group for patients with all cancer types. Analysis based on grounded theory was utilized to identify themes and theoretical constructs.

Results: With regard to patient conceptualizations of religion and spirituality, three categories emerged: (1) Spirituality is intertwined with organized religion; (2) Religion is one manifestation of the broader construct of spirituality; (3) Religion and spirituality are completely independent, with spirituality being desirable and religion not. Religion and spirituality played a central role in patients' coping with cancer, providing comfort, hope, and meaning. Patients diverged when it came to spiritual support, with some enthusiastic about interventions incorporating their spiritual values and others stating that they already get this support through religious communities.

Significance of results: Spirituality plays a central role in the cancer experience of this underserved ethnically-diverse population. While spirituality seems to be a universal concern in advanced cancer patients, the meaning of spirituality differs across individuals, with some equating it with organized religion and others taking a more individualized approach. It is important that psychosocial interventions are developed to address this concern. Future research is needed to further explore the different ways that patients conceptualize spirituality and to develop spiritually-based treatments that are not "one size fits all."

KEYWORDS: Oncology, Minority, Spirituality, Patient Preference, Advanced Cancer

INTRODUCTION

Spirituality and religion (S/R) are often brought to the forefront during times of serious illness. Studies show that 50%–95% of cancer patients rate S/R as personally important (Brady et al., 1999; Jenkins & Pargament, 1995; Peteet, 1985; Roberts et al., 1997; True et al., 2005; Vellone et al., 2006). Unfortunately, there appears to be a gap between what is important to patients and what they are receiving, as many studies have highlighted the presence of unmet spiritual needs. Unmet existential needs have been ranked among the highest supportive care needs of cancer patients (Hodgkinson et al., 2007). One study of the psychosocial needs of gynecological cancer patients found that 32% of patients expressed the need for someone with whom to discuss spiritual questions (Miller, Pittman & Strong, 2003). A study

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of advanced cancer patients revealed that 72% of patients reported their spiritual needs were supported minimally or not at all by the medical system, and almost half did not feel they received spiritual support from their religious community (Balboni et al., 2007).

The prevalence of unmet S/R needs is alarming given the central role spirituality and religion can play in helping patients cope with cancer. Patients with higher levels of psycho-spiritual well-being are able to cope better with terminal illness, and often find meaning in the illness experience (Lin & Bauer-Wu, 2003). Patients report that religious beliefs and practices provide them with comfort, hope, and meaning (Koenig, 2004). Religion and spirituality can also promote a sense of optimism and control, and often provide a community for support (Koenig, 2009). One study found that among hospitalized older adults, almost 90% of patients report using religion to cope, and over 40% reported religion as the top factor keeping them going (Koenig, 1998). While there is a lack of research on the efficacy of spiritual interventions, the few studies that are available demonstrate that spiritual interventions can be quite helpful and are well-received by patients (Breitbart et al., 2010; Cole & Pargament, 1999; Kristeller et al., 2005).

Religious coping is especially common in ethnic minority populations. Both Hispanic and African-American cancer patients report a greater level of religiosity/spirituality (Bourjolly, Kerson & Nuamah, 1999; Mickley & Soeken, 1993) and use of spiritual coping (Culver et al., 2004) than their white counterparts. One study found that significantly more black women than white women use God as a means of support (Bourjolly & Hirshman, 2001). "Spiritual healing" was one of the most common complementary medicine modalities used among Blacks (36%–57%) and Hispanics (26%) (Alferi et al., 2001; Lee et al., 2000). Despite the emphasis placed on S/R by ethnic minority individuals, unmet spiritual and existential needs are particularly prevalent in ethnic minority cancer patients (Moadel et al., 1999).

There seems to be a consensus that religion and spirituality are valuable resources for coping with cancer, especially in ethnic minority populations, and that religion and spirituality are areas of significant need for patients. Therefore, we were surprised to see that in our population, when given the choice between participating in a "Spiritual Support Group" or a "Stress Management Education Group," 66.7% chose to participate in the stress management education group (Moadel et al., 2012). This qualitative study was designed to expand on our earlier work with advanced cancer patients from an ethnically diverse largely underserved Bronx, New York community enrolled in the "Mind-Body Study" of support group interventions. The purpose of this qualitative study is as follows: (1) Explore conceptualizations of religion and spirituality among a highly spiritual population; (2) Investigate the role of R/S in helping patients cope with advanced cancer; and (3) Examine interest in R/S support.

METHODS

Participants

Patients were recruited for the Mind-Body Study from the outpatient clinics at Montefiore Einstein Center for Cancer Care in the Bronx, New York between June 2007 and January 2010. The Bronx community is made up of nearly 1.4 million residents, many of whom are indigent and ethnic minorities. According to the 2010 U.S. Census data, the Bronx is the poorest borough in New York City with 28.4% living below the poverty line. The major racial/ethnic groups represented are Hispanics (54%), blacks (30%), and non-Hispanic whites (11%) (United States Census, 2010). The Mind-Body Study was designed to provide Bronx cancer patients with much-needed psychosocial support. The Primary Investigator of the Mind-Body Study was Dr. Alyson Moadel, and the study was funded by a Research Scholars Grant by the American Cancer Society. Eligible patients included those with any type of cancer who were on treatment or stage III or IV. A convenience sample of patients who had participated in the Mind-Body Study was invited to participate in the second phase of the study. Attempts were made to contact all living participants who had participated in the initial phase of the study. Patients were contacted by phone and asked if they would like to participate in a follow-up to the original study, in which they would be asked to further describe their cancer experiences and express their needs and preferences. Patients were told participation was completely optional. All patients who were still living, had a diagnosis of advanced cancer, and were able and willing to participate took part in this study. This phase was limited to those with advanced disease. Reasons for not participating included medical obstacles, emotional burden, and transportation difficulties.

Study Procedure

The intervention for the Mind-Body Study consisted of attending eight weekly sessions of the group of one's choice. The stress management group was based on a psycho-educational model and focused on helping patients adapt to and cope with cancer. The spiritual group centered on spiritual and

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existential themes, and was chosen to address the unique existential challenges of living with advanced cancer as well as the high self-reported spiritual/existential needs reported by African-American and Hispanic patients in our population. A battery of measures was administered at baseline, two months, and four months. For the qualitative phase of this study, a semi-structured qualitative interview was developed by the research team that included questions on coping techniques, interest in psychosocial support, and spiritual and emotional needs and concerns, and conducted among a subsample of convenience of 12 patients. A qualitative component was deemed appropriate in light of the dearth of research available on the experiences and needs of this understudied population. Interviews were performed in person and scheduled to provide optimal convenience for the patients. All interviews were conducted by the same interviewer, and were digitally recorded and transcribed. There was one exception in which the participant refused to sign the consent to record. This interview was hand recorded.

Analysis

A line-by-line content analysis of transcribed data was performed based on grounded theory. Three coders independently read each interview transcript and selected and coded all content related to religion and spirituality. The group of coders together identified repeating ideas among coded text and developed them into themes. Discrepancies between coders were identified and resolved. Similar themes were then grouped together to create abstract theoretical constructs.

RESULTS

Subjects

Patient demographics are provided in Table 1. Patients were primarily female and middle aged adults. Over half of the participants were black and most were Protestant or Catholic. A variety of cancer types were represented. Notably, all patients self identified as spiritual, religious or both.

Patient Conceptualizations of R/S

There was a large degree of heterogeneity in how patients conceptualized and related to religion and spirituality. Three primary groups emerged (See Fig. 1). The first group of individuals conceptualized religion and spirituality as one and the same. R/S is central to the lives of these individuals and they see no distinction between the two terms, using them interchangeably. For instance, when asked how spiritual support might be helpful, one patient answered:

> I think to continue to have hope, and if they had a ministry in here sometimes I think maybe they could talk to people. I think it would help, for me.

Individuals in the second group also valued both religion and spirituality. However, they acknowledged a distinction between the meanings of the two terms. They saw religion as one piece, but not the entirety of, their spirituality, and reported finding spirituality in other realms too, such as nature and literature.

Table 1. *Demographic and disease characteristics of the sample*

Characteristic	Category	($N = 12$)
Gender	Female	10
	Male	2
Age mean (range)		58.75 (43–73)
Ethnicity	Black	7
	White	3
	Hispanic	2
Cancer type	Hematologic	4
	Breast	3
	Ovarian	2
	Colorectal	1
	Prostate	1
	Bladder	1
Religion	Protestant	6
	Catholic	4
	Jewish	2
Religious/spiritual?	R only	2
	S only	5
	R and S	5

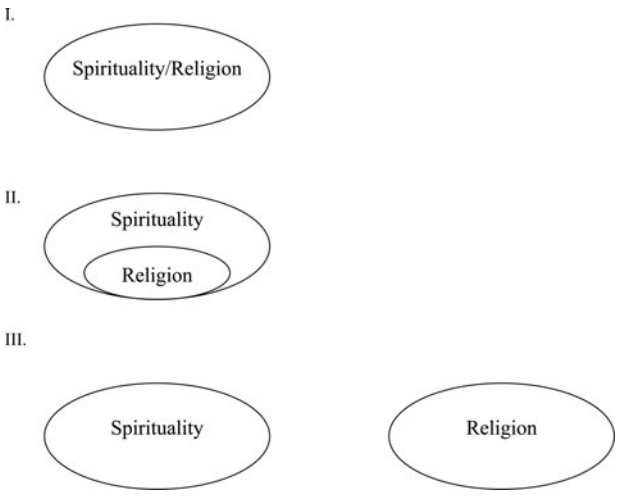

Fig. 1. Categories of Religious/Spiritual Identity.

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For example, when asked what type of support is helpful, one patient answered:

> Going through reading my book [the Bible] and going on my walks, those are just support. As a matter, I'm glad I have my car, because I go to the beach. The beach is a very spiritual thing.

The third group saw religion and spirituality as completely independent constructs. Furthermore, while these individuals endorsed being spiritual, they all specified that they were not religious. To these patients, spirituality was entirely divorced from religion. For example, one patient stated:

> I'm not a religious person, I don't attend any services, I don't follow through with stuff like that, because I don't get anything out of it. Nature was where I found healing... to me God is everything that's out there. You know, that's God. All of creation. It's not possible that by chance all of this could exist. You and I exist... The trees, the air. It's just—I'm totally amazed by it. I'm totally in love with the whole thing.

The Role of R/S in Coping with Cancer

All patients cited R/S as being an important aspect of their cancer experience, and R/S themes fit into the patients' cancer stories in a variety of ways. Many patients saw cancer as a journey, and found within it the potential for growth and meaning-making. They noted that with the challenge presented by cancer comes the opportunity for personal development.

> Every day is like a challenge. But it's for a reason. You rise above it in that, okay, you see so many people in worse circumstances. And so I just look at it as a day-to-day journey up a hill... I just think it was something that was given to me to travel through and make yourself a better person.

Patients also displayed a sense of gratitude for positive shifts in their illness, and described being thankful for being alive. While some patients acknowledged that the question of "why me?" does arise, many stated they have come to a place of "why not me?"

> Well the question "why me?" is not my question. I mean, it's "why not me?" Why not anybody? Why anybody? You never know. So that's not my question. I don't really ask that too much.

Some subjects also saw spiritual themes as necessary for survival. They spoke about hope and faith as imperatives. For these patients, a spiritual mindset was not optional—it was a must.

> I feel that if you don't have hope and don't feel you're going to get better, then you're sinking your own self because you're not making yourself better. You're saying, I don't want to be here, you know? So why are you talking negative? You know, think positive...have some hope.

Patients cited their continued survival as evidence that their faith was "working." They reasoned that their still being alive was direct proof of the efficacy of prayer, hope, and belief.

> To continuously have faith. Continuously to have hope...I see the results right now for myself. Because it's been a year, and I'm still here.

Do Spiritual Patients Prefer Spiritual Support?

Religious or spiritual themes emerged in every interview, and all patients spoke about the importance of religion or spirituality to their cancer experience. However, valuing the spiritual did not always translate into interest in spiritual support, and a great deal of variation in interest in spiritual support was observed among those who were spiritually centered.

One group of individuals expressed a strong preference for religious and spiritual support. In light of the centrality of spirituality in these patients' lives, a spiritual intervention was their obvious choice. To these patients, spirituality and religion provided a framework through which they conceptualized the world. Therefore, they felt that through addressing spiritual concerns, issues like stress and coping would be taken care of. They opted for spiritual support in order to "kill two birds with one stone," as addressing the spiritual would also extinguish stress.

> If I'm stressed, I go to God and he helps me. So the spiritual that we could manage in the group could help me with my stress. So I guess like they say, you'd kill two birds with one stone.

These individuals felt that a spiritual support group for patients with cancer would fill an important niche. They reasoned that cancer and spirituality were the two central components of their lives, so they had a strong interest in blending the two. Even those who felt supported by their church felt there was a certain level of comfort and understanding which could only be offered by fellow cancer patients.

Another group of patients emerged at the opposite end of the continuum. While these patients also endorsed religion and spirituality as central to their experiences, they reported that they were already getting ample spiritual support from their religious communities. Therefore, they were not interested in receiving spiritual support through our services. These patients conveyed the belief that they already have all that they need spiritually and religiously. These patients were either not interested in psychosocial support or expressed interest in areas of support they were not already receiving, such as stress management.

> I mean I don't need anything now, outside, because I have it already. I'm getting it every day. Every moment of my life I receive spiritual support somehow. In my life in general. It's all there. It's all there already.

DISCUSSION

Results of the current study shed light on the constructs of religion and spirituality as conceptualized by an ethnically diverse group of patients living with advanced cancer, all of whom are self described as spiritual, religious, or both. For all these patients, R/S themes played a key role in their cancer experience and permeated their cancer narratives. Religious and spiritual themes shaped the framework through which they experienced their illness. They described seeing the cancer experience as a journey with the potential for growth and meaning-making, and some even saw religion and spirituality as necessary for survival. These results give qualitative support to the previous findings (Brady et al., 1999; McClain, Rosenfeld & Breitbart, 2003; Nelson et al., 2002) connecting spirituality with emotional wellbeing.

Among this group of patients, a variety of perspectives was expressed regarding the relationship between the constructs of religion and spirituality. This difference in conceptualization mirrors the ongoing debate in the literature over how to define religion and spirituality. Some of our patients saw religion and spirituality as entirely distinct constructs, reflecting the recent polarization of religion and spirituality in the literature. Koenig, McCullough and Larson, in their *Handbook of Religion and Health*, lay out the key differences between religion and spirituality as widely conceptualized in recent times. Religion is seen as community focused; observable, measurable, and objective; formal, orthodox, and organized; consisting of behavior-oriented, outward practices; authoritarian in terms of behavior; and consisting of doctrine separating good and evil. Spirituality, on the other hand, is conceptualized as individualistic; less visible and measurable and more subjective; less formal, organized, and systematic; emotionally-oriented, inwardly directed; not authoritarian, little accountability; and unifying, not doctrine-oriented (Koenig, McCullough & Larson, 2001). Similar understandings are seen in our patients who described the separate roles religion and spirituality played in their lives, and in those who described themselves as spiritual but not religious.

On the other hand, for other patients, religion and spirituality were thought of as one and the same. This echoes how the two terms were historically conceptualized, with "religion" encompassing both the individual and the institutional (Hill & Pargament, 2003). For example, William James, perhaps the most well-known figure in the study of psychology and religion, put both firsthand, experiential religion and secondhand, institutional, inherited religion under the umbrella of "religion" (James, 1902). It appears that like many of our patients, the average individual sees little distinction between the two terms. This finding is supported by various studies, including one study of 1713 Canadian adults which found that over half of those reporting spiritual needs expressed those needs using religious terminology (e.g. increased faith in God, prayer, church attendance) (Bibby, 1995). Another study found that when given the option, most American individuals describe themselves as spiritual and religious. Additionally, they describe the two concepts as having at least some overlap and integrated both spirituality and religion with traditional organizational beliefs and practices (Zinnbauer, 1997).

A novel component of our work is that it explores patient preferences for psychosocial support. Our qualitative data combined with our quantitative work paints a picture of the factors that go into a patient's preference for spiritual support. As reported previously (see appendix), our quantitative data revealed that over two thirds of participants opted for a stress-management support group over a spiritual support group. Additionally, those who chose spiritual support appear to be doing better, as they are more highly educated; have higher levels of overall quality of life, physical well-being, emotional well-being, and functional well-being; lower anxiety levels; and are more likely to use humor to cope. It appears stress-management is chosen by those in more active distress, while spiritual support is a sort of luxury that patients will only utilize when they are not in crisis. This suggests a hierarchy of needs where more acute, pressing needs like stress and anxiety must be addressed before patients can devote time and energy to higher level existential needs.

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The fact that even in a population where almost all patients are religious and/or spiritual over two thirds opted for stress-management instead of spiritual support further highlights just how complex and multi-faceted spirituality and spiritual support are. Results of the qualitative phase of this study indicate that spirituality and religion mean very different things to different people. Likewise, different patients have very different needs and desires for spiritual support from programs such as ours. These needs and desires are largely independent of a patient's self-identification as religious and/or spiritual. For example, a clinician may have two devoutly Catholic patients, one who is enthusiastic about a group focused on the spiritual themes she holds so dear, while the second feels that his spiritual needs are adequately covered by the church community.

As the above example reveals, eliciting basic spiritual/religious information such as a patient's religious identification or the importance of spirituality in his or her life does not provide sufficient information for making decisions regarding the suitability of a spiritual intervention for a particular patient. Instead, more in-depth discussion is needed to explore the meaning of spirituality and religion to a specific patient and how this translates into his preferences for support. Various measures have been proposed to adequately assess a patient's spiritual history (Maugans, 1996; Puchalski, 2002). It is important that this sort of measure be utilized, as it is crucial that a patient's unique spiritual and religious identity be elicited so that he or she can best be matched with S/R support that will fit his specific needs.

This study has multiple limitations. Firstly, it includes only a small subset of the larger quantitative study. Those patients who were able to come in for qualitative interviews may be experiencing less limitations than those who were unable to come in. Secondly, this population is largely female. Therefore, some phenomena explored here may be less applicable in a male population. Work on spirituality and religion in men specifically would be helpful in determining whether the findings here are applicable to men. Finally, all participants in this study were willing and able to sign up for a support group. It is possible that the experiences and characteristics of those who were not interested in a support group would be different than those in our population.

CONCLUSIONS

While many have explored religion and spirituality and their linkages with various measures of well-being, the time has come to apply these findings to actual interventions. As Kristeller et al. point out in their recent paper (Kristeller, Sheets, Johnson, & Frank, 2011), there is much variety in how patients relate to religion and spirituality, and this variability calls for increased specificity in matching patients to spiritual and religious interventions. Such an important area of patient wellbeing cannot be neglected or treated in a "one size fits all" manner. It is time we heed the voices of our patients and use their identification of religious and spiritual needs to better meet their psychosocial needs.

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APPENDIX

Table 2. *Baseline Socio-demographic and Psychosocial Differences between Intervention Groups in the Patient Preference Phase (n = 52)*

	Stress Management Group (66.7%)	Spiritual Support Group (31%)
Education*	100% < HS 76% HS 43% HS	0% < HS 24% HS 57% >HS
Frequency of Private Religious Activity (DUREL)**	3.8	5.2
FACT-G: Overall QoL*	59.81	72.36
Physical Wellbeing*	15.58	19.50
Emotional Wellbeing*	14.31	18.19
Functional Wellbeing*	12.50	16.14
BSI-Anxiety*	54.01	46.93
COPE-Humor*	3.92	5.31

*$p < 0.05$, **$p < 0.01$.

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