

Religiousness and Spiritual Support Among Advanced Cancer Patients and Associations With End-of-Life Treatment Preferences and Quality of Life

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A B S T R A C T

Purpose

Religion and spirituality play a role in coping with illness for many cancer patients. This study examined religiousness and spiritual support in advanced cancer patients of diverse racial/ethnic backgrounds and associations with quality of life (QOL), treatment preferences, and advance care planning.

Methods

The Coping With Cancer study is a federally funded, multi-institutional investigation examining factors associated with advanced cancer patient and caregiver well-being. Patients with an advanced cancer diagnosis and failure of first-line chemotherapy were interviewed at baseline regarding religiousness, spiritual support, QOL, treatment preferences, and advance care planning.

Results

Most (88%) of the study population (N = 230) considered religion to be at least somewhat important. Nearly half (47%) reported that their spiritual needs were minimally or not at all supported by a religious community, and 72% reported that their spiritual needs were supported minimally or not at all by the medical system. Spiritual support by religious communities or the medical system was significantly associated with patient QOL ($P = .0003$). Religiousness was significantly associated with wanting all measures to extend life (odds ratio, 1.96; 95% CI, 1.08 to 3.57).

Conclusion

Many advanced cancer patients' spiritual needs are not supported by religious communities or the medical system, and spiritual support is associated with better QOL. Religious individuals more frequently want aggressive measures to extend life.

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INTRODUCTION

Increasing recognition that technical interventions incompletely engage the issues encountered in life-threatening illness^{1,2} has resulted in a growing incorporation of other parameters of health into cancer care, including religion and spirituality.^{3,4} The National Cancer Institute defines religion as a set of beliefs and practices associated with a religion or denomination, and defines spirituality as the search for ultimate meaning through religion or other paths.³ In the *Handbook of Religion and Health*, Koenig et al⁵ similarly highlight the considerable overlap and the distinct characteristics of religion and spirituality. Following this conceptualization, both terms are used when encompassing both domains: religion and/or spirituality (R/S), whereas

when emphasizing one of these domains, the individual term is used (eg, spiritual support and religious activities).

Between 50% and 95% of cancer patients view R/S as personally important⁶⁻¹⁰ and experience spiritual needs,¹¹⁻¹³ particularly minority patients.¹³ Research demonstrates an association between R/S and improved coping and quality of life (QOL).¹⁴⁻¹⁸ Negative religious coping (eg, perceiving illness as divine punishment) can also arise in the setting of illness and is associated with distress and QOL decrements.^{14,19,20} The National Consensus Project for Quality Palliative Care, a consortium of palliative care organizations establishing national palliative care guidelines, includes attention to patient R/S as one of eight clinical practice domains. These guidelines provide a framework for providing spiritual support—care that acknowledges patient R/S and

attends to spiritual needs—in a clinical setting. However, little is known about how life-threatening illness influences needs for and experiences of spiritual support, how religiousness affects end-of-life treatment preferences, and how spiritual support influences QOL.⁴

In this study, advanced cancer patients were interviewed to assess religiousness and R/S activities before and after the cancer diagnosis, support of spiritual needs by the medical system and by religious communities, the association of spiritual support with patient quality of life, and the relationship of religiousness to treatment preferences and advance care planning.

METHODS

Study Sample

Patients were recruited from August 1, 2002, to August 25, 2005, as part of the Coping With Cancer Study, a multi-institutional investigation of advanced cancer patients and their primary (unpaid) caregivers. Participating sites include Yale Cancer Center (New Haven, CT), Veterans' Affairs Connecticut Healthcare System Comprehensive Cancer Clinics (West Haven, CT), Memorial Sloan-Kettering Cancer Center (New York, NY), Simmons Comprehensive Cancer Care Center (Dallas, TX), and Parkland Hospital Palliative Care Service (Dallas, TX).

Inclusion criteria were diagnosis of advanced cancer (expected prognosis of < 1 year) and failure of first-line chemotherapy; diagnosis at a participating site; age ≥ 20 years; identified unpaid caregiver; and adequate stamina to complete the interview. Patient-caregiver dyads in which either met criteria for dementia or delirium (by neurobehavioral cognitive status examination²¹) or could not speak English or Spanish were excluded. All study participants provided written, informed consent according to protocols approved by each local institutional review board.

Study Measures

After informed consent was obtained, patients participated in a baseline interview (\$25 compensation). Interviewers were trained by research staff from Yale University.

Religiousness and spiritual support. Patients rated the importance of religion to them and the frequency of their religious service attendance and private R/S activities (eg, prayer) before and after the cancer diagnosis. Patients assessed support of their spiritual needs by a religious community (eg, clergy, members of a congregation) on a scale from 1 (not at all) to 5 (completely supported). Patients similarly evaluated support of their spiritual needs by the medical system (eg, doctors, nurses, chaplains). Overall spiritual support (OSS) was assessed as a sum of the answers to these two questions (possible scores, 2 to 10). Patients reported whether they had received visits from a chaplain or from clergy outside of a medical setting. Comfort received from pastoral visits was also assessed. Terms such as religion and spiritual support were not defined for patients to encompass the variety of patient R/S. Appendix Table A1 (online only) lists the religiousness and spiritual support questions.

Religious coping. Pargament's Brief RCOPE²² (14 items) assessed positive religious coping (eg, I have been looking for a stronger connection with God) and negative religious coping (eg, I have been wondering whether God has abandoned me).

QOL. The McGill Quality of Life questionnaire²³ (16 items) assessed patient QOL. It is designed to measure QOL at all stages of life-threatening illness and has been validated previously.^{23,24}

Other patient variables. Age, sex, race/ethnicity, education, and insurance status were reported by the patient. Disease information was obtained from chart review. Zubrod performance score was determined by physician assessment. Patients were also asked whether they wanted all measures to extend life, if they had a living will (LW) or a durable power of attorney (DPOA), and if they had completed a do not resuscitate (DNR) order.

Statistical Analysis

McNemar's test was used to compare R/S activities before and after the cancer diagnosis. Linear regression assessed the relationships of distress and age to religiousness. Linear regression was used to assess the association of OSS to QOL. Univariate models estimated the main effects of OSS as well as religiousness, positive religious coping, negative religious coping, race/ethnicity, sex, age, performance status, and region (northeast v south). The multivariate analysis (MVA) model included all univariate variables entered simultaneously. MVA was repeated with the existential and support QOL domains removed to assess the relationship of OSS to QOL without these potentially overlapping domains. Logistic regression was used to assess the relationship between religiousness and the following three items: preference for all measures to extend life; presence of a LW or DPOA; and completion of a DRN order. Univariate models estimated the main effects of religiousness as well as race/ethnicity, sex, age, performance status, and region. A two-sided $P < .05$ was considered significant. Analyses were performed with SAS version 9.1 (SAS Institute Inc, Cary, NC).

RESULTS

Sample Characteristics

Of 538 eligible patients, 338 were enrolled. The most common reasons for nonparticipation included "not interested" ($n = 94$),

Table 1. Characteristics of Sample Patients (N = 230)

Characteristic	No. of Patients	%
Sex		
Male	125	54
Female	105	46
Age, years		
Mean	56.8	
SD	12.1	
Race/ethnicity		
White	140	61
Black	44	19
Hispanic	39	17
Asian	5	2
Other	2	1
Education, years		
Mean	12.4	
SD	4.1	
Health insurance	144	63
Recruitment site		
Yale	119	52
Parkland	91	40
VACCC	11	5
Simmons	9	4
Diagnosis information		
Lung cancer	57	25
Colorectal cancer	33	14
Breast cancer	18	8
Pancreatic cancer	18	8
Other*	104	45
Metastatic disease	189	82
Zubrod performance score		
0	30	13
1	107	47
2	57	25
3	29	13
4	7	3

Abbreviations: SD, standard deviation; VACCC, Veterans' Affairs Connecticut Healthcare System Comprehensive Cancer Clinics.

*The remaining patients had cancer types representing < 5% of the sample.

“caregiver refuses” (n = 27), and “too upset” (n = 18). Nonparticipants were more likely to be white (73% v 62%; $P = .01$), older (60.9 v 57.1 years; $P = .002$), and to report more distress (2.76 v 2.40; $P = .005$) on a scale from 1 (minimal to no distress) to 5 (extreme distress). Participants and nonparticipants did not differ significantly by sex or education. Sixty-seven patients accrued at Memorial Sloan-Kettering Cancer Center were excluded because it was not a participating site for all measures; some measures were added in a subsequent grant. An additional 41 patients had missing data.

The characteristics of the sample patients (N = 230) are described in Table 1. Of 100 participants from southern institutions, 61% were nonwhite, and of 130 participants from northeastern sites, 22% were nonwhite ($P < .0001$).

Religiousness and Religious Activities

Religion was considered very important by 156 participants (68%), somewhat important by 47 participants (20%), and not important by 27 participants (12%). More African Americans (89%) and Hispanics (79%) reported religion to be very important compared with whites (59%; $P = .001$ and $P = .03$, respectively). Increasing patient-reported distress at the time of study recruitment was significantly associated with increasing religiousness ($P = 0.01$), whereas age was not associated with religiousness ($P = 0.53$). Fifty-six percent attended religious services once a month or more before their cancer diagnosis. This decreased to 44% after the cancer diagnosis ($P = .0002$). Private R/S activities were performed at least daily by 47% before their diagnosis and by 61% after the diagnosis ($P < .0001$).

Support of Advance Cancer Patient Spiritual Needs

Patients' spiritual needs were supported by religious communities to a large extent or completely for 38%, whereas 47% reported their spiritual needs were supported by religious communities to a small extent or not at all. When examining religious patients (n = 203), 40% were supported to a small extent or not at all. Among religious individuals, African Americans were completely supported by religious communities more frequently than whites (52% v 19%; $P < .0001$) and Hispanics (52% v 26%; $P = .005$). Seventy-two percent stated that their spiritual needs were met to a small extent or not at all by the medical system. Forty-two percent of patients reported little to

no support of their spiritual needs from either a religious community or the medical system.

A total of 133 patients (52%) had received visits from chaplains or other clergy. Most whites (83%), African Americans (94%), and Hispanics (100%) stated that the pastoral visit provided some comfort or a lot of comfort. Four patients (3%) reported that the visit made them uncomfortable.

Relationship of Spiritual Support to QOL and Religiousness to Treatment Preferences and Advance Care Planning

Tables 2 and 3 detail univariate analyses and MVAs of the relationship of spiritual support to patient QOL and religiousness to treatment preferences and advance care planning. MVA revealed higher OSS to be positively associated with patient QOL ($P = .0003$). MVA was performed with the support and the existential domains removed from the QOL scores, and OSS remained a significant predictor ($\beta = 1.5$, SE = 0.4; $P = .0007$).

Table 4 lists patient treatment preferences and advance care planning. In MVA, increasing religiousness was associated with preferring all measures to extend life (odds ratio [OR], 1.96; 95% CI, 1.08 to 3.57). Although in univariate analysis increasing religiousness was negatively associated with having a LW or a DPOA, in adjusted analyses the effect was no longer significant; only nonwhite race/ethnicity was significantly inversely related to the likelihood of completing a LW or a DPOA (OR, 0.23; 95% CI, 0.12 to 0.44). On MVA, religiousness was not significantly associated with having a DNR order; only nonwhite race/ethnicity (OR, 0.41; 95% CI, 0.20 to 0.82) and northeastern site (OR, 0.42; 95% CI, 0.21 to 0.85) were inversely related to having a DNR order.

DISCUSSION

This study demonstrates that religion is important to most advanced cancer patients, particularly to African Americans and Hispanics. Yet many patients become less able to participate in religious communities after becoming ill. Although private religious activities may address some spiritual needs, many advanced cancer patients do not have support from a religious community or from the medical system

Table 2. Univariate and Multivariate Predictors of Patient QOL (N = 230)

Predictor	Univariate Analyses			Multivariate Analysis*			Model r^2
	β	SE	P	β	SE	P	
Spiritual support	1.6	0.6	.01	2.7	0.7	.0003	0.25
Religiousness	0.8	2.2	.73	-2.5	2.9	.39	
Positive religious coping	-0.1	0.2	.69	-0.2	0.3	.45	
Negative religious coping	-1.25	0.5	.008	-1.3	0.5	.007	
Nonwhite	6.8	3.1	.03	8.4	3.2	.009	
Female	-3.9	3.1	.20	-6.3	2.8	.03	
Age	0.2	0.1	.20	0.4	0.1	.003	
Zubrod PS	-7.4	1.5	<.0001	8.3	1.5	<.0001	
Northeast†	-2.6	3.1	.40	-3.4	3.2	.27	

Abbreviations: QOL, quality of life; PS, performance status.

*Multivariate analysis performed with all variables entered simultaneously into the model.

†Northeastern recruitment sites v southern recruitment sites.

Table 3. Univariate and Multivariate Predictors of Patient Treatment Preferences and Advance Care Planning (N = 230)

Outcome	Predictor	Univariate Analyses			Multivariate Analyses*		
		OR	95% CI	P	OR	95% CI	P
Wanting all measures to extend life	Religiousness	2.14	1.23 to 3.72	.007	1.96	1.08 to 3.57	.03
	Nonwhite	3.08	1.67 to 5.66	.0003	2.42	1.23 to 4.77	.01
	Female	0.92	0.51 to 1.66	.78	0.80	0.42 to 1.52	.49
	Age	0.96	0.94 to 0.99	.002	0.97	0.94 to 0.99	.01
	Zubrod PS	1.07	0.79 to 1.45	.66	1.03	0.74 to 1.45	.85
	Northeast†	0.56	0.31 to 1.01	.06	1.09	0.54 to 2.20	.80
Having a LW and/or a DPOA	Religiousness	0.62	0.42 to 0.91	.01	0.75	0.49 to 1.56	.20
	Nonwhite	0.22	0.12 to 0.39	<.0001	0.23	0.12 to 0.44	<.0001
	Female	0.77	0.46 to 1.29	.32	0.84	0.47 to 1.49	.55
	Age	1.02	1.00 to 1.04	.08	1.01	0.99 to 1.04	.32
	Zubrod PS	0.93	0.71 to 1.21	.57	0.95	0.71 to 1.28	.73
	Northeast†	1.70	1.00 to 2.88	.05	0.82	0.43 to 1.56	.54
Having a DNR order	Religiousness	0.88	0.59 to 1.33	.55	0.81	0.51 to 1.27	.36
	Nonwhite	0.55	0.29 to 1.02	.06	0.41	0.20 to 0.82	.01
	Female	1.27	0.71 to 2.28	.42	1.40	0.75 to 2.59	.29
	Age	1.01	0.98 to 1.03	.49	1.01	0.98 to 1.04	.54
	Zubrod PS	1.19	0.88 to 1.59	.26	1.16	0.84 to 1.59	.36
	Northeast†	0.64	0.36 to 1.15	.13	0.42	0.21 to 0.85	.02

Abbreviations: OR, odds ratio; PS, performance status; LW, living will; DPOA, durable power of attorney; DNR, do not resuscitate.

*Multivariate analysis performed with all variables entered simultaneously into the model.

†Northeastern recruitment sites v southern recruitment sites.

at a particularly vulnerable period of their illness trajectory. Our study showed that support of patients' spiritual needs was associated with an important clinical outcome—improved QOL. Furthermore, we uncovered a provocative association between religiousness and desires for aggressive treatment to extend life.

The finding that religion was important to most participants is consistent with prior studies of cancer patients⁶⁻¹⁰ and with the finding that 96% of US adults express a belief in God and 70% identify religion as one of the most important influences in their lives.²⁵ Furthermore, as in other studies,^{26,27} African Americans and Hispanics rated religion as important more frequently than whites. Patients reported a decrease in religious service attendance after their cancer diagnosis consistent with prior studies,^{28,29} and they indicated a corresponding increase in private R/S activities. The finding that patients' private R/S activities increase may reflect patients' decreasing ability to attend religious services or that patients are seeking a deeper religiousness or

spirituality at the end of life. Roberts et al,¹⁰ in a study of 108 women with gynecologic malignancies, found that 49% reported becoming more religious after their diagnosis, with none becoming less religious. As life-threatening illness confronts individuals with the reality and proximity of their mortality, R/S meaning may become increasingly important to patients at the end of life.

Spiritual needs were minimally supported by religious communities for approximately half of the participants, with support being greatest among African Americans. In addition, most patients reported that the medical system (including chaplains) provides little spiritual support. With pastoral visits usually representing only a sliver of the medical experience and physicians infrequently addressing R/S issues with patients,³⁰⁻³³ many patients might view their medical experience as devoid of spiritual support.

Numerous barriers prevent physicians from contributing to the provision of spiritual support at the end of life. These include the more recent historical development of a separation between R/S and medicine.⁵ Support for maintaining this separation is largely based on the concern that physicians might impose a specific set of R/S beliefs on patients, thereby compromising patient autonomy.^{34,35} Balancing this potential danger should be a recognition that R/S can contribute to coping with serious illness, and that in failing to address this domain of QOL, physicians may be neglecting an important force for healing and wholeness. There is considerable evidence that patients and individuals in the community support the integration of R/S into medical practice.^{32,33,36-38} This is not to suggest that the role of physicians is to be spiritual counselors; clearly physicians must respect their professional boundaries. However, physicians can participate appropriately in the spiritual care of patients by recognizing spiritual needs and advocating for attention to R/S concerns as routine features of clinical care.³⁹ Furthermore, for physicians to facilitate the delivery of spiritual care, practical

Table 4. End-of-Life Treatment Preferences and Advance Care Planning (N = 230)

Question	Response	No. of Patients	%
Would you want the doctors here to do everything possible to keep you alive even if you were going to die in a few days anyway?	Yes	59	26
	No	171	74
Do you have a signed living will or durable power of attorney for health care, both or neither?	Living will and/or durable power of attorney	109	47
	Neither	121	53
Have you completed a do not resuscitate (DNR) order?	Yes	62	27
	No	168	73

barriers should be addressed, including inadequate training in evaluating spiritual needs.⁴⁰

Patients who reported greater spiritual support from outside and within the medical system had better QOL even after removing the support and existential QOL domains and controlling for other predictors of QOL. As physical health wanes, spiritual health may increasingly play a central role in determining patient well-being. This hypothesis is supported by the findings of Steinhauser et al⁴¹ in an investigation of factors important at the end of life among a random, national sample of 340 patients with advanced illness. Of nine attributes ranked by patients (eg, presence of pain, dying at home), being at peace with God was second in importance, with pain control only marginally ranking higher. Spiritual support may help patients find their peace with God and hence maintain QOL by providing them with opportunities to express spiritual concerns and receive spiritual counsel. Rummans et al,⁴² in a randomized, controlled trial of a multidisciplinary intervention in advanced cancer patients that included a spiritual component, found prospectively that patients receiving the intervention had improved QOL in comparison with controls. In addition, Kristeller et al⁴³ alternately assigned cancer patients to a short, semistructured exploration of spiritual concerns by their oncologist and prospectively found a statistically significant improvement in depressive symptoms, QOL, and in a sense of interpersonal caring from their oncologist.

Higher levels of religiousness, in our study and those of others,⁶ were found to be associated with wanting all measures to extend life. Religious individuals may feel that because their illness is in divine hands, there is always hope for a miraculous intervention. In addition, religious individuals may place a value on life that supersedes potential harms of aggressive attempts to sustain life. Furthermore, Jenkins and Pargament⁹ have proposed, religiousness may assist in preserving meaning and connection to others in the face of illness, and this may uphold patients' desires to continue living. Although we, like others,⁶ found that religiousness was inversely associated with having an advance directive in our univariate analysis, we believe that this relationship was confounded by its association with race/ethnicity—a strong predictor in this sample for not having an advance directive. The additional finding that region (despite adjusting for factors such as race and religiousness) was associated with having a DNR order suggests that completion of these orders is partly a function of geographic differences in institutional practices.

The potential role that R/S plays in influencing patient QOL and in shaping treatment preferences suggests that the spiritual history⁴⁴ should become a routine part of clinical care among patients with advanced illness, especially in caring for African American and Hispanic patients. Additional practices that have the potential to improve patient well-being include training of non-pastoral medical staff to identify spiritual needs and to improve awareness of R/S resources. The increasing presence of medical school courses on R/S is evidence of progress in this regard.⁴⁵ Improved integration of pastoral staff into the medical team also has the potential to improve management of the spiritual aspects of illness. Finally, improving connections between the medical system and outside religious communities may facilitate incorporation of spiritual supporters into patient care. Some first steps toward this

integration include inquiring about patients' spiritual supports and inviting their involvement in care. Direct communication between the medical team and spiritual supporters when desired by patients may also be beneficial at times.

Limitations of this study include the potential influence of selection bias, particularly the possibility of differences in R/S between participants and nonparticipants. Nonwhites were more likely to participate and were more religious. However, increasing reported distress at the time of recruitment was associated with nonparticipation and, among participants, greater religiousness. Although there were age differences in participation, age was not related to religiousness in the sample. Furthermore, the reasons for nonparticipation suggest another potential source for selection bias; for example, nonparticipants may have been not interested in participating because they were not religious or spiritual. However, the Coping With Cancer study assessed R/S as one of many coping factors, reducing the likelihood that nonparticipation was because of a specific disinterest in R/S. In addition, it is unclear in the questions regarding spiritual support how many patients did not have spiritual needs, although prior studies suggest that most cancer patients express spiritual needs.¹¹⁻¹³ Finally, the cross-sectional nature of this study limits the interpretation of the relationship between spiritual support and QOL to a hypothesis-generating association.

Attention to R/S has been recognized as an important component of end-of-life care, as illustrated by the National Consensus Project for Quality Palliative Care guidelines.⁴ However, additional research is essential to their appropriate implementation. Methods for meeting patient spiritual needs should be explored, and the impact of such interventions should be assessed. In addition, the appropriate roles of various health care providers (eg, physicians, nurses) in managing spiritual needs should be clarified. Although incorporating R/S into care requires delicacy, attention to this dimension of health has the potential to enhance patient well-being at the end of life.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The authors indicated no potential conflicts of interest.

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Appendix

The Appendix is included in the full-text version of this article, available online at www.jco.org. It is not included in the PDF version (via Adobe® Reader®).