

Provision of Spiritual Support to Patients With Advanced Cancer by Religious Communities and Associations With Medical Care at the End of Life

Tracy A. Balboni, MD, MPH; Michael Balboni, PhD; Andrea C. Enzinger, MD; Kathleen Gullivan, PhD; M. Elizabeth Paulk, MD; Alexi Wright, MD; Karen Steinhauser, PhD; Tyler J. VanderWeele, PhD; Holly G. Prigerson, PhD

Importance: Previous studies report associations between medical utilization at the end-of-life (EoL) and religious coping and spiritual support from the medical team. However, the influence of clergy and religious communities on EoL outcomes is unclear.

Objective: To determine whether spiritual support from religious communities influences terminally ill patients' medical care and quality of life (QoL) near death.

Design, Setting, and Participants: A US-based, multisite cohort study of 343 patients with advanced cancer enrolled from September 2002 through August 2008 and followed up (median duration, 116 days) until death. Baseline interviews assessed support of patients' spiritual needs by religious communities. End-of-life medical care in the final week included the following: hospice, aggressive EoL measures (care in an intensive care unit [ICU], resuscitation, or ventilation), and ICU death.

Main Outcomes and Measures: End-of-life QoL was assessed by caregiver ratings of patient QoL in the last week of life. Multivariable regression analyses were performed on EoL care outcomes in relation to religious community spiritual support, controlling for confounding variables, and were repeated among high religious coping and racial/ethnic minority patients.

Results: Patients reporting high spiritual support from religious communities (43%) were less likely to receive hospice (adjusted odds ratio [AOR], 0.37; 95% CI, 0.20-

0.70 [$P = .002$]), more likely to receive aggressive EoL measures (AOR, 2.62; 95% CI, 1.14-6.06 [$P = .02$]), and more likely to die in an ICU (AOR, 5.22; 95% CI, 1.71-15.60 [$P = .004$]). Risks of receiving aggressive EoL interventions and ICU deaths were greater among high religious coping (AOR, 11.02; 95% CI, 2.83-42.89 [$P < .001$]; and AOR, 22.02; 95% CI, 3.24-149.58 [$P = .002$]; respectively) and racial/ethnic minority patients (AOR, 8.03; 95% CI, 2.04-31.55 [$P = .003$]; and AOR, 11.21; 95% CI, 2.29-54.88 [$P = .003$]; respectively). Among patients well-supported by religious communities, receiving spiritual support from the medical team was associated with higher rates of hospice use (AOR, 2.37; 95% CI, 1.03-5.44 [$P = .04$]), fewer aggressive interventions (AOR, 0.23; 95% CI, 0.06-0.79 [$P = .02$]) and fewer ICU deaths (AOR, 0.19; 95% CI, 0.05-0.80 [$P = .02$]); and EoL discussions were associated with fewer aggressive interventions (AOR, 0.12; 95% CI, 0.02-0.63 [$P = .01$]).

Conclusions and Relevance: Terminally ill patients who are well supported by religious communities access hospice care less and aggressive medical interventions more near death. Spiritual care and EoL discussions by the medical team may reduce aggressive treatment, highlighting spiritual care as a key component of EoL medical care guidelines.

JAMA Intern Med. 2013;173(12):1109-1117.

Published online May 6, 2013.

doi:10.1001/jamainternmed.2013.903

Author Affiliations are listed at the end of this article.

SPIRITUAL CARE—CARE THAT recognizes patient religion and/or spirituality and attends to spiritual needs—has been incorporated into national care quality guidelines, including those of the National Consensus Project for Quality Palliative Care¹ and the Joint Commission.² Data suggest that provision of spiritual care by medical teams to

terminally ill patients is associated with better patient quality of life (QoL), greater

*See Invited Commentary
at end of article*

hospice utilization, and less aggressive medical interventions at the end of life (EoL).³ However, spiritual care from the medical team is infrequent in the setting

of advanced illness,^{4,5} an omission likely due to multiple factors, including practical barriers such as insufficient resources (eg, chaplaincy staff,⁶ practitioner training, and time⁷) and concerns regarding offending patients.⁷

Though spiritual care from the medical team is typically absent, patients facing advanced illness often are connected to religious communities that act as key providers of spiritual support.⁴ Hence, spiritual care guidelines include religious communities as principal providers of spiritual care to patients.^{1,8} Understanding the impact of religious community spiritual care on patient EoL outcomes is critical to characterizing optimal spiritual care provision. Furthermore, given the salient role that religious communities often play among racial/ethnic minority^{9,10} and high religious coping patients¹¹—patients at risk for greater aggressive EoL care¹¹⁻¹³—understanding associations of religious community spiritual care with EoL outcomes is of particular relevance in these populations.

The Coping With Cancer Study is a multi-institutional study of patients with advanced cancer designed to investigate how psychosocial and religious and spiritual factors influence patients' medical care and QoL near death. The purpose of this study was to examine how provision of spiritual care by religious communities influences patient QoL and medical care at the EoL, particularly among high religious coping and racial/ethnic minority patients.

METHODS

STUDY SAMPLE

Patients were recruited from September 1, 2002, to August 28, 2008, from 7 outpatient sites: Dana-Farber Cancer Institute and Massachusetts General Hospital, Boston; New Hampshire Oncology Hematology, Hookset; Parkland Hospital and Simmons Cancer Center, Dallas, Texas; Veterans Affairs Connecticut Comprehensive Cancer Clinics, West Haven; and Yale University Cancer Center, New Haven, Connecticut. Eligibility criteria included an advanced cancer diagnosis with disease refractory to first-line chemotherapy; age 20 years or older; presence of an informal (nonpaid) caregiver; and adequate stamina to complete the interview. Exclusion criteria included patient or caregiver meeting criteria for dementia or delirium by neurocognitive examination and inability to speak English or Spanish. All participants provided written informed consent according to protocols approved by each participating center's human subjects committee.

STUDY PROTOCOL

Research staff underwent 2 days of training in the study's operating procedures. Potential participants were identified from outpatient clinic schedules. On enrollment, patients underwent a baseline interview. Patients' medical records were reviewed to extract disease and treatment variables. A second assessment was performed within 2 to 3 weeks after the participant's death, including medical record extraction to obtain EoL medical care information and a postmortem interview of a formal or informal caregiver familiar with the care the patient received in the final week of life.

Of 944 eligible patients approached, 670 (71%) accepted participation. The most common reasons for nonparticipation included "not interested" (n=109) and "caregiver refuses" (n=35).

There were no significant differences between nonparticipants and participants in sex, age, race, or education. At the time of completion of active study follow-up (August 28, 2008), 379 had died and a postmortem interview was performed. Of these 379 patients, 36 lacked complete postmortem or spiritual care data, resulting in a final sample of 343 (91%).

BASELINE MEASURES

Spiritual Care Variables

Spiritual support from religious communities was assessed by the question, "To what extent are your religious/spiritual needs being supported by your religious community (eg, clergy, members of your congregation)?" Spiritual care from the medical team was assessed with the question, "To what extent are your religious/spiritual needs being supported by the medical system (eg, doctors, nurses, chaplains)?" Response options to both items included "not at all," "to a small extent," "to a moderate extent," "to a large extent," or "completely supported" and were dichotomized (median split for religious community spiritual support) into low ("not at all," "to a small extent," or "to a moderate extent") and high ("to a large extent" or "completely supported") spiritual support. Patients were also asked whether they had received chaplaincy services (yes/no).

Religious Variables

Patients rated religion as "not at all," "somewhat," or "very important." Pargament's Brief RCOPE,¹⁴ a previously validated questionnaire, measured positive religious coping (score range, 0-21). Given our previous report indicating greater aggressive EoL care among patients endorsing high (median score, >12) positive religious coping,¹¹ positive religious coping was similarly dichotomized.

Other Baseline Variables

The McGill QoL questionnaire is a validated instrument^{15,16} designed to measure QoL at all stages of life-threatening illness and includes physical, psychological, overall, existential, and social support subscales. The patient-physician relationship was assessed with 5 items measuring trust, mutual respect (2 items), feeling viewed as a whole person, and comfort asking questions about care (range of possible scores, 0-5). Patient reports of having had an EoL discussion with their physician (yes/no), documentation of advance directives (yes/no), and the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment)-validated question regarding patients' preferences for aggressive vs comfort care¹⁷ also were assessed. Age, sex, race/ethnicity (dichotomized to non-Hispanic whites vs racial/ethnic minorities), education, and insurance status were patient reported. Karnofsky Performance Status Scale score was obtained by physician assessment.

EoL OUTCOMES

EoL Care

Hospice care at EoL was defined as receipt of inpatient or outpatient hospice vs no hospice in the last week of life. Receipt of aggressive EoL care was defined as receipt of care in an intensive care unit (ICU), ventilation, or resuscitation in the last week of life.¹⁸ Location of death was assessed and categorized as death in an ICU vs other settings.

Table 1. Baseline Characteristics of the Study Sample by Spiritual Support From Religious Communities^a

Characteristic	Total Sample (N = 343)	Religious Community Spiritual Support		P Value ⁱ	
		Low (n = 196)	High (n = 147)		
Age, mean (SD), y	58.3 (12.5)	58.7 (12.7)	57.7 (12.3)	.48	
Male, No. (%)	185 (54)	108 (55)	77 (52)	.58	
Racial/ethnic minorities, No. (%) ^b	128 (37)	57 (29)	71 (48)	<.001	
Married, No. (%)	186 (55)	113 (58)	73 (51)	.23	
Education, mean (SD), y	12.4 (4.0)	12.9 (3.9)	11.7 (4.1)	.01	
Health insurance, No. (%)	193 (57)	128 (66)	65 (45)	<.001	
Karnofsky Performance Status Scale, mean (SD), score ^c	63.2 (16.1)	63.2 (17.4)	63.2 (14.1)	.98	
Recruitment site, No. (%)					
Dana-Farber Cancer Institute/Massachusetts General Hospital	7 (2)	4 (2)	3 (2)	<.001	
New Hampshire Oncology Hematology	67 (20)	51 (26)	16 (11)		
Parkland Hospital (Texas)	154 (45)	66 (34)	88 (60)		
Simmons Comprehensive Cancer Center (Texas)	34 (10)	14 (7)	20 (14)		
Veterans Association of Connecticut Cancer Center	13 (4)	10 (5)	3 (2)		
Yale Cancer Center (Connecticut)	66 (19)	50 (26)	16 (11)		
McGill QoL scale, mean (SD), score ^d	45.1 (14.2)	43.7 (14.7)	47.0 (13.4)		<.001
Existential well-being, mean (SD), score ^d	45.7 (10.2)	44.1 (10.6)	47.8 (9.4)	<.001	
Social support, mean (SD), score ^d	17.2 (3.4)	16.7 (3.6)	18.0 (2.8)	<.001	
Religious tradition, No. (%) ^a					
Catholic	126 (36.8)	84 (43.1)	42 (28.6)	<.001	
Protestant	57 (16.7)	30 (15.4)	27 (18.4)		
Jewish	8 (2.3)	8 (4.1)	0		
Muslim	2 (0.6)	2 (1.0)	0		
Pentecostal	9 (2.6)	3 (1.5)	6 (4.1)		
Baptist	57 (16.7)	16 (8.2)	41 (27.9)		
Other	65 (19.0)	36 (18.5)	29 (19.7)		
No religious tradition	18 (5.3)	16 (8.2)	2 (1.4)		
Religiousness, No. (%)					<.001
Not at all important	38 (11)	37 (19)	1 (1)		
Somewhat important	71 (21)	66 (34)	5 (3.4)		
Very important	234 (68)	93 (47)	141 (96)		
High positive religious coping ^e	175 (52)	66 (35)	109 (75)		
Spiritual support from medical team					
Not at all	143 (42)	106 (54)	37 (25)	<.001	
To a small extent	62 (18)	39 (20)	23 (16)		
To a moderate extent	48 (14)	29 (15)	19 (13)		
To a large extent	53 (15)	17 (9)	36 (24)		
Completely supported	37 (11)	5 (3)	32 (22)		
Receipt of chaplaincy services, No. (%)	158 (46)	67 (42)	91 (58)		<.001
EoL discussion with a physician, No. (%)	126 (37)	69 (35)	57 (39)	.50	
Patient-physician relationship, mean (SD), score ^g	4.8 (0.5)	4.7 (0.5)	4.8 (0.4)	.20	
Preference for aggressive treatment measures at EoL, No. (%)	86 (25)	51 (26)	35 (24)	.77	
Terminal illness awareness, No. (%) ^h	145 (43)	70 (37)	75 (53)	.003	
Advanced care planning, No. (%)	188 (55)	120 (61)	68 (46)	.006	

Abbreviations: EoL, end of life; QoL, quality of life.

^aData were missing in less than 3% of patients for the following variables: marital status, health insurance status, Karnofsky Performance Status, recruitment site, quality of life, existential well-being, social support, religious tradition, positive religious coping, patient-physician relationship, terminal illness awareness, and preferences for aggressive treatment measures at end of life.

^bMinority race ethnicity patients included 66 black, 55 Hispanic, and 5 other race patients.

^cA measure of functional status that is predictive of survival, where 0 is dead and 100 is perfect health.

^dMcGill QoL is validated measure of QoL with 5 domains: overall QoL and physical, psychological, existential, and social support. Existential items and support items were removed and used as separate predictors. Total possible scores for physical, psychological, overall domains ranged from 0 to 70. Possible scores for social support and existential well-being ranged from 0 to 60 and 0 to 20, respectively.

^eA measure of positive religious appraisals in coping with illness (eg, I've been seeking God's love and care) (scale, 0-21). Low and high religious coping groups were dichotomized by the median value of 12. Mean (SD) scores among for the full sample and low and high religious community spiritual support patients were 11.1 (6.5), 8.8 (6.6), and 14.2 (4.9), respectively.

^fA measure of negative religious appraisals in coping with illness (eg, I've been wondering whether God has abandoned me) (scale, 0-21).

^gMeasure of patient-physician relationship (scale, 0-5) assessing patient trust in the physician, sense of being cared for as a "whole person," sense of being respected, respect for the physician, and comfort asking questions about care.

^hTerminal illness awareness indicated by patient rating their health status as "relatively healthy and terminally ill" or "seriously and terminally ill" vs those describing themselves as "relatively healthy" or "seriously but not terminally ill."

ⁱP values in bold are statistically significant.

QoL Near Death

Caregivers assessed patient QoL near death with 3 items assessing psychological distress, physical distress, and overall QoL near death that were summed (range of possible scores, 0-30,

with greater values indicating better QoL). Caregiver assessments of patient QoL near death are considered an adequate surrogate based on the significant positive association between caregiver and patient assessments of baseline patient QoL (McGill QoL scale, $r=0.55$; $P<.001$).

STATISTICAL ANALYSIS

Patient demographic, religious, and disease variables were compared among high and low religious community spiritual support groups with *t* tests and χ^2 tests for continuous and ordinal/dichotomous variables, respectively. Rates of receipt of EoL medical care and ICU deaths among those receiving high vs low spiritual support were examined with χ^2 tests.

Simultaneous multivariable logistic regression models assessed relationships of baseline spiritual care to the EoL care measures. All models were adjusted for variables potentially related to spiritual care and EoL care, including race,^{13,19} site,²⁰ EoL treatment preferences,^{21,22} health insurance status, EoL discussion,^{21,23} terminal illness awareness, advance care planning,¹⁹ positive religious coping,¹¹ and medical team spiritual support.³ Simultaneous multivariable linear regression models were used to examine the relationship of religious community spiritual support to QoL at EoL. Given data supporting an association between EoL care and QoL near death,²¹ the model was adjusted for EoL medical care received (eg, hospice, ICU death). The QoL model was also adjusted for baseline QoL domains and spiritual support from the medical team.³ Additional confounders considered for EoL care and QoL models were age, sex, race and health insurance status (automatically entered for EoL care models), education, marital status, performance status, chaplaincy services, and religious tradition. Variables were entered into the model if the bivariable association was $P < .10$ and retained when $P < .05$ after controlling for other confounders.

To examine associations of religious community spiritual care and EoL outcomes among high religious coping and racial/ethnic minority patients, multivariable models were repeated according to median split positive religious coping and among racial/ethnic minority patients. For these analyses, we tested statistically for heterogeneity in odds ratios (ORs) across subgroups defined by minority race and by religious coping. Wald χ^2 tests assessed differences in estimates according to source of spiritual support (religious communities vs medical teams). After determining that high religious community spiritual support was associated with greater aggressive EoL care, we assessed whether spiritual support from the medical team and EoL discussions—interventions associated with reduced aggressive EoL care^{3,21}—may have utility in reducing aggressive EoL care among these patients. Multivariable logistic regression models were used to examine relationships of medical team spiritual support³ and EoL discussions²¹ among patients reporting high spiritual support from religious communities. Furthermore, among patients well-supported by religious communities, rates of EoL medical care according to receipt of medical team spiritual support and EoL discussions were examined with χ^2 tests.

Statistical analyses were performed with SAS version 9.2 (SAS Institute Inc). All reported *P* values are 2-sided and considered significant when $< .05$.

RESULTS

SAMPLE CHARACTERISTICS

Sample characteristics are given in **Table 1**. Patients reporting high support of their spiritual needs were more likely to be racial/ethnic minorities, were less educated, and had lower rates of health insurance. They also reported better QoL, existential well-being, and social support. There were no differences in frequency of EoL discussions or treatment preferences; however,

patients receiving high levels of support from religious communities were more likely to be aware that they were terminally ill and less likely to have advanced care planning.

RELIGIOUS COMMUNITY SPIRITUAL SUPPORT AND EoL QoL

Patients died a median of 116 (interquartile range, 54-255) days after the baseline interview. Univariable and multivariable regression analyses showed no significant relationships between patients' baseline spiritual support from religious communities and QoL near death (β [SE], 0.82 [0.86] [$P = .34$] and 0.24 [0.95] [$P = .80$], respectively). Among high religious coping and racial/ethnic minority patients, no significant associations were found between religious community spiritual support and QoL near death in adjusted analyses (β [SE], -1.58 [-1.31] [$P = .45$] and -2.17 [1.48] [$P = .15$], respectively).

RELIGIOUS COMMUNITY SPIRITUAL SUPPORT AND EoL MEDICAL CARE

Figure 1 shows EoL medical care received among patients reporting low and high spiritual support from religious communities in the full sample, high religious coping patients, and racial/ethnic minority patients. **Table 2** gives multivariable regression analyses examining the relationships between spiritual support from religious communities and EoL medical care, revealing significant associations between high spiritual support and less hospice, greater aggressive medical interventions, and greater ICU deaths. Associations with aggressive care were stronger in high religious coping and racial/ethnic minority patients; formal interaction tests were statistically significant for aggressive care (P values for interaction, .04 for race and .01 for religious coping) and trending for death in an ICU for religious coping (P value for interaction, .06). **Figure 2** shows the contrasting influence of the source of spiritual support on EoL care outcomes. In all cases, the associations between spiritual support from religious communities and EoL outcomes were significantly different from, and in the opposite direction of, spiritual support from medical teams; differences were more pronounced for high religious coping and racial/ethnic minority patients.

MEDICAL TEAM SPIRITUAL SUPPORT AND EoL DISCUSSIONS AMONG PATIENTS RECEIVING HIGH SPIRITUAL SUPPORT FROM RELIGIOUS COMMUNITIES

Figure 3 shows rates of EoL medical care among patients receiving high spiritual support from religious communities according to receipt of medical team spiritual support and EoL discussions. In multivariable regression analyses, patients highly supported by religious communities who reported receipt of spiritual support from their medical team had greater odds of receiving hos-

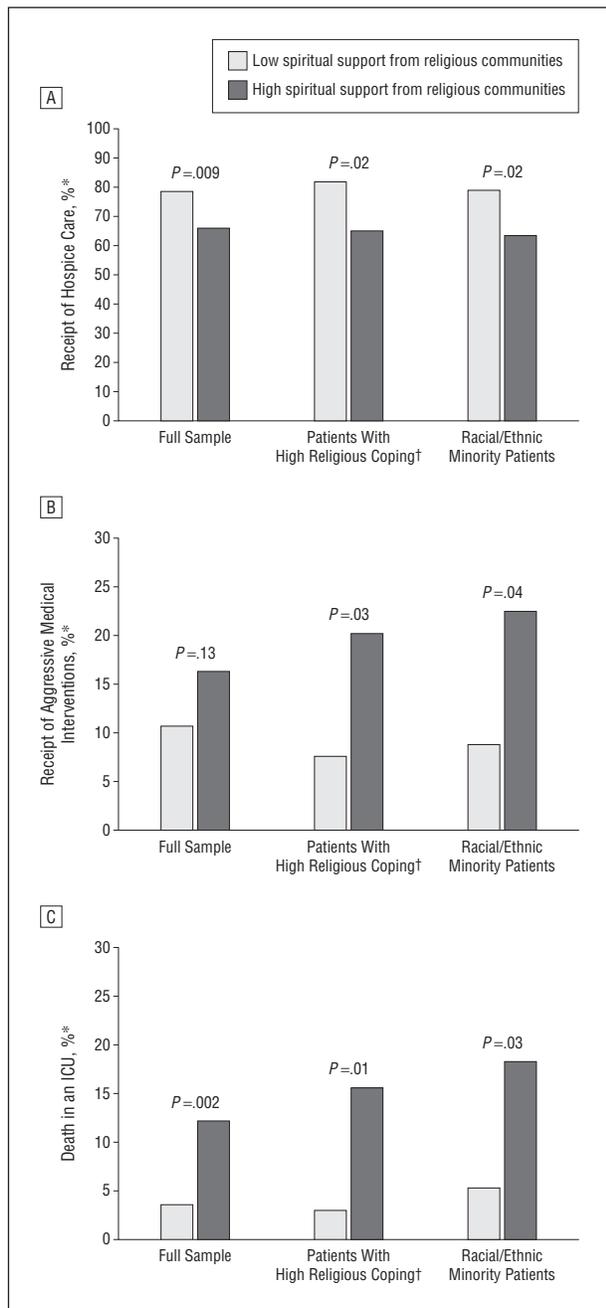


Figure 1. Spiritual support from religious communities. Rates of hospice care (A), aggressive medical interventions (B), and intensive care unit (ICU) death (C) in the full sample (N = 343), patients with high religious coping (n = 175), and racial/ethnic minority patients (n = 128). *Hospice is inpatient or home hospice care in the last week of life, and aggressive medical interventions include receipt of ventilation, resuscitation, or care within an ICU in the last week of life. Full sample rates of hospice care, aggressive medical interventions, and death in an ICU are 73.2%, 13.1%, and 7.3%, respectively. †Religious coping is a patient's reliance on their religious/spiritual beliefs to cope with and understand illness and was measured using Pargament's validated RCOPE (religious coping) instrument (score range, 0-21). Patients with high religious coping were those who scored at or above the median, and of these patients, 63% (n = 109) reported high spiritual support from religious communities and 37% (n = 66) reported low spiritual support from religious communities.

pice care (adjusted OR [AOR], 2.37; 95% CI, 1.03-5.44 [P = .04]) and had lower odds of receiving aggressive EoL interventions (AOR, 0.23; 95% CI, 0.06-0.79 [P = .02])

or dying in an ICU (AOR, 0.19; 95% CI, 0.05-0.80 [P = .02]). End-of-life discussions were associated with less aggressive medical interventions near death (AOR, 0.12; 95% CI, 0.02-0.63 [P = .01]) but were not associated with hospice care (AOR, 2.37; 95% CI, 0.95-5.91 [P = .06]) or ICU deaths (AOR, 0.22; 95% CI, 0.04-1.29 [P = .09]).

DISCUSSION

This study demonstrates that patients receiving high levels of spiritual support from religious communities are less likely to receive hospice care and are more likely to receive aggressive medical interventions at the EoL and die in an ICU setting. These findings remained after controlling for potential confounding factors, such as race and advance care planning. Furthermore, these findings were strongest among racial/ethnic minority and high religious coping patients, populations at greater risk for aggressive interventions at the EoL.^{11,13,19} Among patients receiving high levels of spiritual support from religious communities (43% of our sample), provision of spiritual support by the medical team and EoL discussions were associated with reduced aggressiveness of EoL care. These findings suggest that a possible intervention among patients receiving high religious community spiritual support is the medical team's provision of spiritual support and EoL discussions in order to reduce aggressive care near death in this population.

Our results suggest that the content of spiritual care is a key factor influencing patients' medical decisions, particularly given the disparate influences of spiritual care from religious communities compared with spiritual care provided by medical teams. In contrast to medical teams, religious congregations may be unaware of the biomedical realities surrounding terminal illness and hence may not be addressing issues of death and dying owing to lack of clarity regarding when or whether death will occur. In addition, within many religious traditions including Christian traditions—most of our sample, in keeping with US religious demographics²⁴—there is a strong belief in miracles.²⁵⁻²⁷ Religious communities, in supporting their ill congregants, may be emphasizing and reinforcing a belief in the potential for miraculous healing. Why might this belief result in *more* aggressive medical care, when one might rather conclude that this should motivate a belief in divine miracles that do not require medical technologies? One possibility is that religious people consider medicine to be a primary means of divine intervention. This is supported by findings of a telephone survey of 1033 individuals living in the Southeast, within which 80% endorsed a belief that God acts through physicians to cure illness.²⁷ Hence, religious congregations may view choosing to withhold medical technologies as curtailing the principal avenue by which divine healing can take place or even taking the trajectory of the person's life out of "God's hands."^{28,29} This latter concept touches on religious sentiments regarding the sanctity

Table 2. Multivariable Analyses of High vs Low Spiritual Support From Religious Communities and Associations With End-of-Life Hospice, Aggressive Medical Interventions, and Death in an ICU in the Full Sample, High Religious Coping Patients, and Racial/Ethnic Minority Patients^a

High vs Low Religious Community Spiritual Support	Receipt of Hospice Care ^b		Receipt of Aggressive Medical Interventions ^b		Death in an ICU	
	AOR (95% CI)	P Value	AOR (95% CI)	P Value	AOR (95% CI)	P Value
Full sample (n = 318) ^c	0.37 (0.20-0.70)	.002	2.62 (1.14-6.06)	.02	5.22 (1.71-15.60)	.004
High religious coping patients (n = 168) ^c	0.27 (0.11-0.67)	.005	11.02 (2.83-42.89)	<.001	22.02 (3.24-149.58)	.002
Racial/ethnic minorities (n = 124) ^c	0.17 (0.05-0.54)	.003	8.03 (2.04-31.55)	.003	11.21 (2.29-54.88)	.003

Abbreviations: ICU, intensive care unit; AOR, adjusted odds ratio.

^aModels adjusted for race, positive religious coping, religious tradition, northeast vs southern region, health insurance status, medical team spiritual support, end-of-life treatment preferences, terminal illness awareness, advance care planning, and end-of-life discussions. Sex was included in models examining receipt of hospice and death in an ICU. Results did not differ when examining religious community spiritual support as a nondichotomized predictor (retaining the original 5-point ordinal scale).

^bHospice is inpatient or home hospice care in the last week of life, and aggressive medical interventions included receipt of ventilation, resuscitation, or care within an ICU in the last week of life.

^cSample size was reduced from 343 (total sample), 175 (high religious coping patients), and 128 (racial/ethnic minority patients) owing to missing data, less than 3% of patients for all variables.

of human life and ethical concerns regarding the potential to violate that sanctity,³⁰ which may further motivate the continuation of aggressive medical therapies, even in the setting of advanced terminal illness.

Another possible mechanism by which religious community spiritual support may result in greater aggressive care is that religious communities may frequently emphasize perseverance through and hope found within suffering. Coupled with a strong belief in the potential for miraculous healing, religious communities' emphasis on hope, meaning, and perseverance in illness may not only uphold but also may constrain patients' spiritual approach to terminal illness to fighting their disease. This buttressing of patients' hope and endurance in illness is perhaps in part reflected in the baseline association of high religious community spiritual support with better patient QoL and existential well-being (as well as greater social support), though the patients were *more* aware of the terminal nature of their illness and their performance status did not differ from those not well-supported by religious communities. However, high religious community spiritual support was not associated with patient QoL near death (even after adjusting for medical care received), in contrast both to its association with QoL at baseline and to the previously reported prospective association of medical team spiritual support with better patient well-being near death.³ These contrasting findings may again reflect religious communities' focus on spiritual support in fighting disease—a form of support that may uphold QoL earlier in the course of advanced illness when combating illness remains feasible but may become increasingly incongruent or even in conflict with patients' spiritual needs as death becomes imminent. Conversely, medical teams providing spiritual support may be better addressing spiritual needs that become increasingly central to patient QoL as terminal illness progresses, such as finding acceptance and spiritual peace in dying.³¹

The study findings suggest possible means of reducing the risk of greater aggressive EoL care among patients receiving high spiritual support from religious communities—provision of spiritual care and of EoL

discussions from the medical team—and highlight these central elements of quality palliative care.¹ The results also underscore the potential role of spiritual care in addressing EoL racial/ethnic disparities because racial/ethnic minorities are at risk for greater aggressive EoL care^{12,32} and are frequently highly supported by religious communities (55% of the racial/ethnic minority patients in this sample). The findings suggest that by addressing EoL decisions in a manner that embraces patients' spiritual values and goals, the medical team is assisting patients in avoiding aggressive interventions at the EoL. Mechanisms for these associations may be that medical teams are engaging those religious/spiritual factors influencing EoL medical decisions (eg, belief in miracles) and that this engagement is encouraging patients to adopt less-intensive approaches to EoL care. For example, through such engagement, some patients and families may discover that a belief in miracles can be as firmly held in the hospice setting as it is in the ICU or that choosing to withhold aggressive EoL measures does not constitute taking matters out of "God's hands."²⁸ Furthermore, these findings emphasize the need for clinician spiritual care training, particularly given their frequent lack of training and its association with increased spiritual care provision.^{5,33} Finally, these findings highlight the potential value of faith-based initiatives among religious communities regarding EoL issues, as evidenced by faith-based programs successfully addressing health disparities in other settings.³⁴⁻³⁶

Study limitations include the unclear content of spiritual support provided by religious communities. Furthermore there may be incomplete adjustment or unknown confounders not incorporated into the multivariable models. The study's generalizability to those with noncancerous terminal illnesses and to other cultural contexts with differing religious demographics also remains unclear. Further studies on spiritual care and EoL outcomes within other patient populations and examining specific spiritual care content are required.

In conclusion, terminally ill patients receiving high spiritual support from religious communities receive more-intensive EoL medical care, including less hospice, more aggressive interventions, and more ICU deaths,

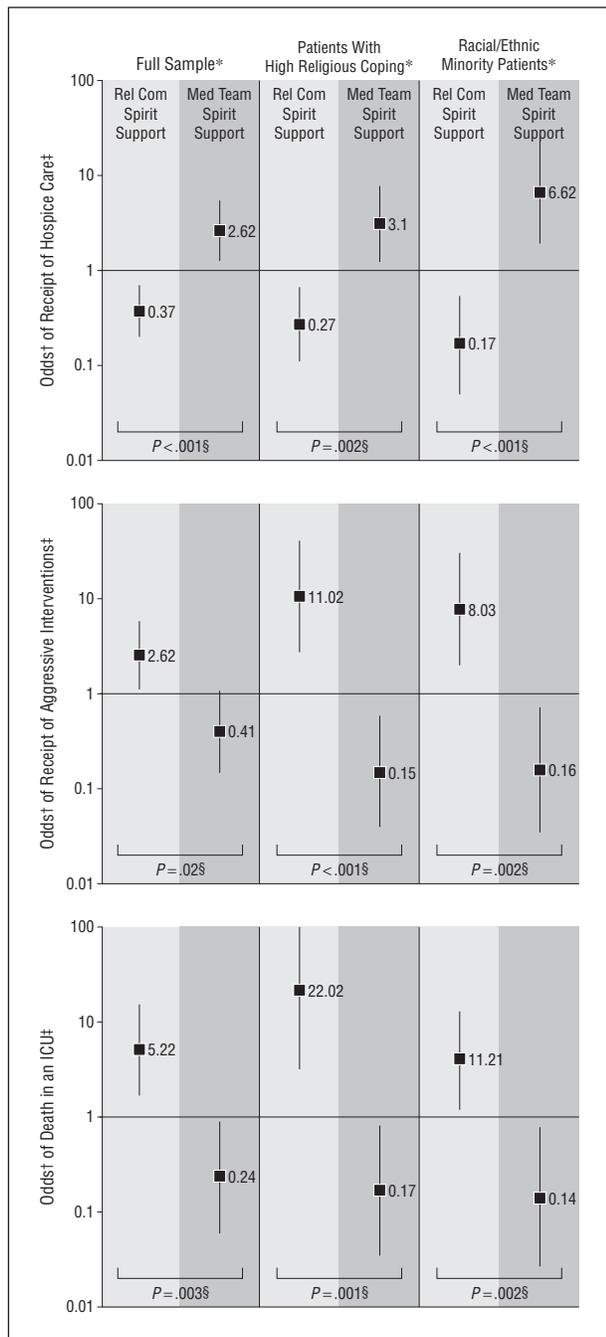


Figure 2. Comparison of sources of spiritual support and their adjusted associations with end-of-life medical care in the full sample, patients with high religious coping, and racial/ethnic minority patients. ICU indicates intensive care unit; Rel Com Spirit Support, Religious Community Spiritual Support; Med Team Spirit Support, Medical Team Spiritual Support. *Sample size reduced from 343 (total sample), 175 (patients with high religious coping), and 128 (racial/ethnic minority patients) owing to missing data (<3% for all variables). †Odds ratios and 95% confidence intervals are shown. Models adjusted for race, positive religious coping, religious tradition, northeast vs southern region, health insurance status, Med Team Spirit Support, end-of-life treatment preferences, terminal illness awareness, advance care planning, and end-of-life discussions. Sex was included in models examining receipt of hospice and death in an ICU. ‡Hospice is inpatient or home hospice care in the last week of life and aggressive medical interventions include receipt of ventilation, resuscitation, or care within an ICU in the last week of life. §Wald χ^2 for comparison of odds ratios.

particularly among racial/ethnic minority and high religious coping patients. The provision of spiritual care and

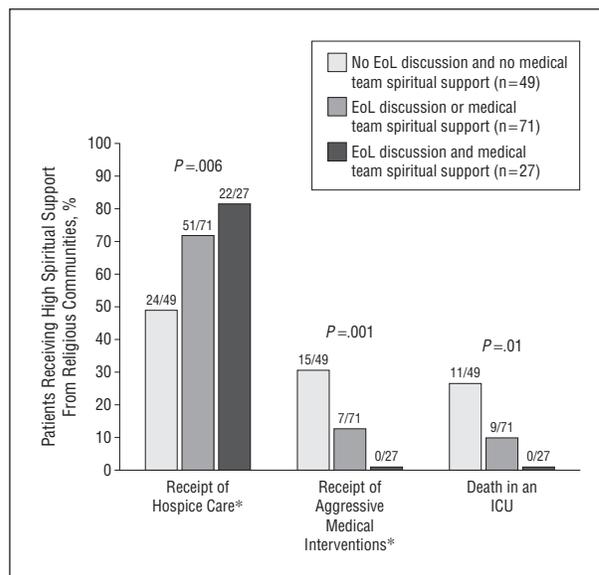


Figure 3. End-of-life (EoL) medical care among 147 patients receiving high spiritual support from religious communities according to receipt of EoL discussions and high spiritual support from the medical team. *Hospice is inpatient or home hospice care in the last week of life, and aggressive medical interventions include receipt of ventilation, resuscitation, or care within an intensive care unit (ICU) in the last week of life.

EOL discussions by medical teams to patients highly supported by religious communities is associated with reduced medical care intensity near death. These findings underscore the need for research defining optimal spiritual care provision to patients with advanced illness, greater clinician spiritual care training, and faith-based initiatives engaging religious communities regarding EoL issues.

Accepted for Publication: February 4, 2013.

Published Online: May 6, 2013. doi:10.1001/jamainternmed.2013.903

Author Affiliations: Center for Psychosocial Epidemiology and Outcomes Research (Drs T. A. Balboni, M. Balboni, Enzinger, Wright, and Prigerson), McGraw/Patterson Center for Population Sciences (Drs T. A. Balboni, M. Balboni, Enzinger, Wright, and Prigerson), and Departments of Radiation Oncology (Dr T. A. Balboni) and Psychosocial Oncology and Palliative Care (Drs T. A. Balboni, M. Balboni, and Enzinger), and Division of Women's Cancers (Dr Wright), Department of Medical Oncology (Drs Enzinger and Wright), Dana-Farber Cancer Institute, Boston, Massachusetts; Departments of Radiation Oncology (Dr T. A. Balboni), Psychiatry (Drs M. Balboni and Prigerson), and Medicine (Dr Wright) and Clinical Fellow in Medicine (Dr Enzinger), Harvard Medical School, Boston; Harvard Divinity School, Cambridge, Massachusetts (Dr M. Balboni); Departments of Chaplaincy (Dr Gallivan) and Psychiatry (Dr Prigerson), Brigham and Women's Hospital, Boston; Department of Internal Medicine, University of Texas Southwestern Medical Center, Dallas (Dr Paulk); Department of Medicine, Duke University Medical Center, Durham, North Carolina (Dr Steinhauer); and Departments of Biostatistics and Epidemiology, Harvard School of Public Health, Boston (Dr VanderWeele).

Correspondence: Tracy A. Balboni, MD, MPH, Dana-Farber Cancer Institute, 450 Brookline Ave, Boston, MA 02215 (tbalboni@iroc.harvard.edu).

Author Contributions: Drs T. A. Balboni and Prigerson had full access to all the data in the study and take full responsibility for the integrity of the data and the accuracy of the data analysis. *Study concept and design:* T. A. Balboni, Enzinger, and Prigerson. *Acquisition of data:* Paulk, VanderWeele, and Prigerson. *Analysis and interpretation of data:* T. A. Balboni, M. Balboni, Enzinger, Gallivan, Wright, Steinhauser, VanderWeele, and Prigerson. *Drafting of the manuscript:* T. A. Balboni, M. Balboni, and VanderWeele. *Critical revision of the manuscript for important intellectual content:* T. A. Balboni, M. Balboni, Enzinger, Gallivan, Paulk, Wright, Steinhauser, VanderWeele, and Prigerson. *Statistical analysis:* T. A. Balboni, Wright, and VanderWeele. *Obtained funding:* Prigerson. *Administrative, technical, and material support:* Prigerson. *Study supervision:* VanderWeele and Prigerson.

Conflict of Interest Disclosures: None reported.

Funding/Support: This research was supported by grant MH63892 from the National Institute of Mental Health and grants CA 106370 and CA 156732 from the National Cancer Institute (Dr Prigerson); by the Fetzer Foundation (Drs Prigerson and Paulk); by an American Society of Clinical Oncology Young Investigator Award and Career Development Award and a Healthcare Chaplaincy/John Templeton Foundation Award (Dr T. A. Balboni); by a University of Chicago Program in Religion and Medicine Faculty Scholars Award (Dr M. Balboni); and by a John Templeton Foundation grant (Dr VanderWeele).

Previous Presentation: These data were presented in abstract form as an oral presentation at the 2010 American Society of Clinical Oncology Annual Meeting; June 5, 2010; Chicago, Illinois.

REFERENCES

1. National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care. 2nd ed. Pittsburgh, PA: National Consensus Project for Quality Palliative Care; 2009. <http://www.nationalconsensusproject.org>. Accessed June 28, 2010.
2. The Joint Commission. PC.02.02.13. 3.7.0.0 ed: E-dition; 2011. http://www.jointcommission.org/assets/1/6/LTC_Core_PC.pdf. Accessed March 28, 2013.
3. Balboni TA, Paulk ME, Balboni MJ, et al. Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. *J Clin Oncol*. 2010;28(3):445-452.
4. Balboni TA, Vanderwerker LC, Block SD, et al. Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *J Clin Oncol*. 2007;25(5):555-560.
5. Balboni MJ, Sullivan A, Amobi A, et al. Why is spiritual care infrequent at the end of life? spiritual care perceptions among patients, nurses, and physicians and the role of training. *J Clin Oncol*. 2013;31(4):461-467.
6. VandeCreek L, Siegel K, Gorey E, Brown S, Toperzer R. How many chaplains per 100 inpatients? benchmarks of health care chaplaincy departments. *J Pastoral Care*. 2001;55(3):289-301.
7. Curlin FA, Lawrence RE, Odell S, et al. Religion, spirituality, and medicine: psychiatrists' and other physicians' differing observations, interpretations, and clinical approaches. *Am J Psychiatry*. 2007;164(12):1825-1831.
8. Puchalski C, Ferrell B, Virani R, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med*. 2009;12(10):885-904.
9. The Pew Forum on Religion & Public Life. *Changing Faiths: Latinos and the Transformation of American Religion*. 2007. <http://www.pewforum.org/uploadedfiles/Topics/Demographics/hispanics-religion-07-final-mar08.pdf>. Accessed January 25, 2013.
10. The Pew Forum on Religion & Public Life. *A Religious Portrait of African-Americans*. 2009; <http://www.pewforum.org/A-Religious-Portrait-of-African-Americans.aspx#a>. Accessed August 1, 2012.
11. Phelps AC, Maciejewski PK, Nilsson M, et al. Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. *JAMA*. 2009;301(11):1140-1147.
12. Hanchate A, Kronman AC, Young-Xu Y, Ash AS, Emanuel E. Racial and ethnic differences in end-of-life costs: why do minorities cost more than whites? *Arch Intern Med*. 2009;169(5):493-501.
13. Smith AK, Earle CC, McCarthy EP. Racial and ethnic differences in end-of-life care in fee-for-service Medicare beneficiaries with advanced cancer. *J Am Geriatr Soc*. 2009;57(1):153-158.
14. Pargament KI, Koenig HG, Perez LM. The many methods of religious coping: development and initial validation of the RCOPE. *J Clin Psychol*. 2000;56(4):519-543.
15. Cohen SR, Mount BM, Bruera E, Provost M, Rowe J, Tong K. Validity of the McGill Quality of Life Questionnaire in the palliative care setting: a multi-centre Canadian study demonstrating the importance of the existential domain. *Palliat Med*. 1997;11(1):3-20.
16. Cohen SR, Mount BM, Strobel MG, Bui F. The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease: a preliminary study of validity and acceptability. *Palliat Med*. 1995;9(3):207-219.
17. Hakim RB, Teno JM, Harrell FE Jr, et al; SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. Factors associated with do-not-resuscitate orders: patients' preferences, prognoses, and physicians' judgments. *Ann Intern Med*. 1996;125(4):284-293.
18. Earle CC, Neville BA, Landrum MB, Ayanian JZ, Block SD, Weeks JC. Trends in the aggressiveness of cancer care near the end of life. *J Clin Oncol*. 2004;22(2):315-321.
19. Smith AK, McCarthy EP, Paulk E, et al. Racial and ethnic differences in advance care planning among patients with cancer: impact of terminal illness acknowledgment, religiousness, and treatment preferences. *J Clin Oncol*. 2008;26(25):4131-4137.
20. Morden NE, Chang CH, Jacobson JO, et al. End-of-life care for Medicare beneficiaries with cancer is highly intensive overall and varies widely. *Health Aff (Millwood)*. 2012;31(4):786-796.
21. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008;300(14):1665-1673.
22. Cosgriff JA, Pisani M, Bradley EH, O'Leary JR, Fried TR. The association between treatment preferences and trajectories of care at the end-of-life. *J Gen Intern Med*. 2007;22(11):1566-1571.
23. Prigerson HG. Socialization to dying: social determinants of death acknowledgment and treatment among terminally ill geriatric patients. *J Health Soc Behav*. 1992;33(4):378-395.
24. Pew Research Center. US religious landscape survey. 2008. <http://religions.pewforum.org>. Accessed August 1, 2012.
25. Pew Research Center. *Religion Among the Millennials: Less Religiously Active Than Older Americans, but Fairly Traditional in Other Ways*. 2010. <http://www.scribd.com/doc/97002468/Religion-among-millennials-less-religiously-active-than-older-americans-traditional-in-other-ways>. Accessed August 1, 2012.
26. Widera EW, Rosenfeld KE, Fromme EK, Sulmasy DP, Arnold RM. Approaching patients and family members who hope for a miracle. *J Pain Symptom Manage*. 2011;42(1):119-125.
27. Mansfield CJ, Mitchell J, King DE. The doctor as God's mechanic? beliefs in the Southeastern United States. *Soc Sci Med*. 2002;54(3):399-409.
28. Torke AM, Garas NS, Sexson W, Branch WT. Medical care at the end of life: views of African American patients in an urban hospital. *J Palliat Med*. 2005;8(3):593-602.
29. Sulmasy DP. Spiritual issues in the care of dying patients: ". . .it's okay between me and God." *JAMA*. 2006;296(11):1385-1392.
30. Bülow HH, Sprung CL, Reinhart K, et al. The world's major religions' points of view on end-of-life decisions in the intensive care unit. *Intensive Care Med*. 2008;34(3):423-430.
31. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*. 2000;284(19):2476-2482.
32. Loggers ET, Maciejewski PK, Paulk E, et al. Racial differences in predictors of intensive end-of-life care in patients with advanced cancer. *J Clin Oncol*. 2009;27(33):5559-5564.
33. Epstein-Peterson Z, Sullivan A, Phelps AC, et al. Spiritual care provided by oncology physicians and nurses to advanced cancer patients [abstract]. *J Clin Oncol*. 2012;(30)(suppl):abstract 9116.

34. Kim KH, Linnan L, Campbell MK, Brooks C, Koenig HG, Wiesen C. The WORD (wholeness, oneness, righteousness, deliverance): a faith-based weight-loss program utilizing a community-based participatory research approach. *Health Educ Behav*. 2008;35(5):634-650.
35. Sutton MY, Parks CP. HIV/AIDS prevention, faith, and spirituality among black/African American and Latino communities in the United States: strengthening

scientific faith-based efforts to shift the course of the epidemic and reduce HIV-related health disparities [published online May 28, 2011]. *J Relig Health*. 2011. doi:10.1007/s10943-011-9499-z.

36. Studts CR, Tarasenko YN, Schoenberg NE, Shelton BJ, Hatcher-Keller J, Dignan MB. A community-based randomized trial of a faith-placed intervention to reduce cervical cancer burden in Appalachia. *Prev Med*. 2012;54(6):408-414.

INVITED COMMENTARY

Advancing Research on Spiritual Influences at the End of Life

Balboni and her team¹ continue to highlight the role that religiousness and spiritual support play in the lives of patients with advanced cancer. Given the accumulating evidence linking aspects of religion and spirituality to a variety of health and health care–related outcomes, this line of work is needed to expand the literature to end-of-life (EoL) treatment decisions and well-being. The current study adds to the discussion by addressing the role of religious communities, in addition to spiritual support offered by health care providers and personal religiousness. This study also provides an ideal stepping point from which to discuss several conceptual and methodological issues.

To begin, studies in this area would benefit from the decades of work within the pastoral care field concerning the conceptualization and assessment of spiritual needs among medical patients. Although there is still a lack of consensus over what constitutes core spiritual needs and how to best measure them, most investigators agree that multiple dimensions are involved. For example, one prominent model of spiritual assessment includes the following dimensions: (1) beliefs and meaning; (2) vocation and obligations; (3) experience and emotions; (4) courage and growth; (5) ritual and practice; (6) community; and (7) authority and guidance.² Given the theoretical foundations and clinical experiences used to develop such models, attempts to measure these complex ideas with single items are likely to be inadequate. At the very least, it is important to distinguish between spirituality, which is the broader of the 2 constructs, and religion, which refers primarily to the social-institutional component within this domain. In the current study¹ (and in the numerous other studies based on the Coping With Cancer data set), these 2 concepts are conflated within the measures of spiritual care. Specifically, the primary measure of spiritual care asks how well the patient's religious/spiritual needs are being met by his or her religious community.

The measures of spiritual support used by Balboni et al¹ are also hampered by a lack of specificity regarding the timing and content of the support. In respect to the former, the spiritual support questions were asked in the outpatient clinic approximately 3 to 4 months before death (on average). Nothing is known about support received during the remainder of their illness, including the final

stage. Thus, ideal measures should address at what point, and how frequently, the support is provided. Objective measures of support, such as from chaplains' documentation in medical records, would be one example of how to address some of these concerns. In regard to the content of the spiritual support, it would be valuable to know more about (1) how such assistance is being provided to the patient and (2) which types of support are most or least helpful. Recent developments in theory and research on congregational support systems are useful for thinking about how to advance this line of work related to support received from religious communities. Dimensions of congregational support include instrumental support (goods and services), socioemotional support (making the recipient feel loved, valued, and cared for), and spiritual support (reinforcing core beliefs and helping the recipient understand and live out his or her faith commitments more fully).³ These and other types of assistance can be provided by religious groups via formal programs, informal contacts among religious group members, or interactions with clergy members. Future research on religion/spirituality and EoL decisions would be strengthened by the inclusion of questions related to these kinds of supports in meeting spiritual needs.

Other aspects of religiousness and spirituality that predict well-being in the general population may also deserve consideration in relation to EoL outcomes for terminally ill patients. Among these constructs are (1) meaning or the sense that one's life has had a purpose or positive impact; (2) forgiveness and reconciliation; and (3) emotions such as gratitude. In addition, the role of "spiritual struggles" or negative experiences of spirituality encountered by patients at EoL may be consequential. Three types of spiritual struggles might be particularly relevant.⁴ The first is "divine struggles," in which case a patient might wonder why God, especially a good and loving God, would allow them to suffer so much. This may lead to feelings of divine abandonment or a questioning of divine caring or power. A second type of spiritual struggle may involve religious doubts, in which the patient comes to question core elements of his or her belief system as a consequence of the illness experience and prognosis. Yet, a third type of spiritual struggle is interpersonal, involving relationships with individuals in one's religious community. In the context of terminal illness,