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Providers and Types of Spiritual Care during Serious Illness

LAURA C. HANSON, M.D., M.P.H.,[1] DEBRA DOBBS, Ph.D.,[2]
BARBARA M. USHER, R.N., Ph.D.,[3] SHARON WILLIAMS, Ph.D.,[4]
JIM RAWLINGS, M.Div., D.Min.,[5] and TIMOTHY P. DAALEMAN, D.O., M.P.H.[6]

ABSTRACT

***Objective*: Patients and palliative care experts endorse the importance of spiritual care for seriously ill patients and their families. However, little is known about spiritual care during serious illness, and whether it satisfies patients' and families' needs. The objective of this study was to describe spiritual care received by patients and families during serious illness, and test whether the provider and the type of care is associated with satisfaction with care.**

***Methods*: Cross-sectional interview with 38 seriously ill patients and 65 family caregivers about spiritual care experiences.**

***Results*: The 103 spiritual care recipients identified 237 spiritual care providers; 95 (41%) were family or friends, 38 (17%) were clergy, and 66 (29%) were health care providers. Two-thirds of spiritual care providers shared the recipient's faith tradition. Recipients identified 21 different types of spiritual care activities. The most common activity was help coping with illness (87%) and the least common intercessory prayer (4%). Half of recipients were very or somewhat satisfied with spiritual care, and half found it very helpful for facilitating inner peace and meaning making. Satisfaction with spiritual care did not differ by provider age, race, gender, role, or frequency of visits. Types of care that helped with understanding or illness coping were associated with greater satisfaction with care.**

***Conclusion*: Seriously ill patients and family caregivers experience spiritual care from multiple sources, including health care providers. Satisfaction with this care domain is modest, but approaches that help with understanding and with coping are associated with greater satisfaction.**

INTRODUCTION

THE RELIEF OF SUFFERING is one of the goals of medical care, and may become the primary goal when illness is incurable. To relieve suffering, health care providers must be skilled in treatment for pain, but they may also be called on to attend to emotional and existential causes of suffering. Spiritual care is one way to address these needs. Spiritual care encompasses religious rituals and practices, as well as activities that comfort and support the person who is seriously ill as they search for meaning and for connection to what is infinite or transcendent.

Patients and family caregivers express a desire to have spiritual needs recognized and addressed.[3–6] A recent review found that between 41–94% of patients

[1]Division of Geriatric Medicine, [4]Department of Allied Health, Services, [6]Department of Family Medicine, University of North Carolina, Chapel Hill, North Carolina.
[2]School of Aging Studies, University of South Florida, Tampa, Florida.
[3]Department of Palliative Care and Medical Ethics, University of Pittsburgh Medical Center, Pittsburgh, Pennsylvania.
[5]Pastoral Care, University of North Carolina Hospitals, Chapel Hill, North Carolina.

want their physicians to inquire about spiritual needs.[7] Rigorously designed interview studies demonstrate that stronger spiritual and religious coping are associated with better social support, less psychological distress, better physical health and better quality of life for patients with serious illness. In interviews with patients with advanced cancer, positive religious coping was associated with better overall quality of life, and with better perceived social support.[8] In interviews with older hospitalized patients, those with higher self-reported religiosity also reported better social support and fewer depressive symptoms, with modestly better physical health.[9]

Expert panels for the Institute of Medicine, the National Hospice and Palliative Care Organization, and the Joint Commission on Accreditation of Healthcare Organizations have advocated for attention to the spiritual needs of patients as a standard of practice.[10–12] More recently, consensus practice guidelines for high quality palliative care, endorsed by the National Quality Forum, include a requirement for care to meet spiritual needs.[13]

Operationalizing these guidelines may be difficult, since little is known about the providers or types of spiritual care patients currently experience, or about its effectiveness in meeting their needs or improving their ability to cope with serious illness. Effective spiritual care should help patients and caregivers find meaning, and promote a sense of connection and peace in the face of suffering or death. Few studies have examined the effects of spiritual care on spiritual coping, satisfaction, or value of this care to patients. In a separate study of end-of-life care for long-term care residents, we found that family frequently perceived staff to provide spiritual care, and they associated this care with better overall quality of care.[14] In small clinical trials, structured spiritual care results in modest spiritual and psychological benefits to participating patients.[15–17] Unfortunately, these forms of specialized spiritual care are not widely available, and most seriously ill patients rely on clergy, family and friends, or health care providers.

The overall objective of this study is to describe the providers and types of spiritual care experienced by seriously ill patients and family caregivers. The specific aims of this study were to describe who provides spiritual care, what types of spiritual care activities are provided, and how well it satisfies the needs of those who receive care and to test whether characteristics of the providers, including age, gender, race, relationship, or role in care, and whether or not they shared the recipient's faith tradition, and types of care are associated with satisfaction with this care.

METHODS

Study subjects

Study subjects were recruited from palliative care, family medicine, or geriatric medicine inpatient services and oncology clinics in a university tertiary care health system. Patients were recruited during a 13-month study period from January 2005 to February 2006. They were eligible if they were capable of understanding and responding to interview questions, and if their attending physician judged that it would not be surprising if the patient died within the year. Family caregivers for patients who were determined to have this prognosis were also eligible for interview, regardless of the patient's capacity. Family caregivers were interviewed as potential recipients of spiritual care, not as surrogates for patients' experiences.

Data collection

Data were collected using in-person structured interviews. One investigator contacted treating physicians weekly to identify patients who met the prognostic criterion. Eligible patients and family caregivers were given introductory written information about the study. Those who expressed willingness to participate were approached by one of several trained interviewers who asked for informed consent. These same interviewers conducted the interviews, usually completed in person during hospitalization. However, some interviews were completed by telephone if requested by the study subject.

Study measures

We designed interview questions using Donabedian's quality of care framework, to describe the structure and types of spiritual care activities and their relationship to outcomes of perceived value and satisfaction with care.[18] In the introduction, the interviewer encouraged the patient or family caregiver to answer questions using their own understanding of religious and spiritual needs, and defined spiritual care as "all those things that people did to help you with your own sense of spirituality during this difficult time." If asked, interviewers clarified that spiritual care included, but was not confined to a religion or religious tradition.

All interview measures were pilot tested with four members of the target population for clarity and comprehension, resulting in minor revisions. Spiritual care recipients provided information on demographics. To describe the mood state of care recipients, they an-

swered a validated two-item screen for depressive symptoms, consisting of the following questions, "During the past month, have you often been bothered by feeling down, depressed, or hopeless?" and "During the past month, have you been bothered by little interest or pleasure in doing things?"[19] They answered items about their own religiosity, spirituality, and related practices.[20] Interviewers then asked each person to identify up to three individuals who provided spiritual care to them during the last few months. For each spiritual care provider, recipients were asked to recall that person's age, gender, race, relationship or role in care, and whether or not they shared the recipient's faith tradition.

To ensure that we included all types of spiritual care activities, interviewers began with an open-ended request to recall a particular spiritual care provider and describe spiritual care activities. Interviewers recorded answers verbatim, then for completeness asked about 18 possible types of spiritual care activities, such as "helping you be at peace with God." Investigators generated these items a priori based on a definition of spiritual care,[21] and refined by a review of the literature on the domains of religious and spiritual caregiving.

Table 1. Characteristics of Spiritual Care Recipients

Characteristic	*Total* n = *103 (mean or percent)*	*Patients* n = *38 (mean or percent)*	*Caregivers* n = *65 (mean or percent)*	p *value*[a]
Age (range, mean)	34–98 (65.5)	42–98 (72.9)	34–86 (61.1)	< 0.001
Race				0.19
African American	24 (23.8%)	12 (31.6%)	12 (18.5)	
White	74 (73.2%)	23 (60.5%)	51 (78.5)	
Other	3 (2.9%)	2 (5.3%)	1 (2.6)	
Gender				0.45
Female	71 (68.9%)	25 (65.8%)	46 (70.8)	
Educational attainment				< 0.01
Some high school	17 (16.6%)	11 (28.9%)	6 (9.2)	
High school graduate	21 (20.6%)	10 (26.3%)	11 (6.9)	
Some college	13 (12.7%)	7 (18.4%)	6 (9.2)	
College graduate	46 (45.1%)	8 (21.1%)	38 (58.5)	
Depression (2 items)				0.40
Low (no to both)	43 (41.7%)	17 (44.7%)	26 (40%)	
Medium (yes to one)	36 (35.0%)	10 (26.3%)	26 (40%)	
High (yes to both)	23 (22.3%)	10 (26.3%)	13 (20%)	
Affiliation				0.71
Protestant	71 (68.9%)	29 (76.3%)	42 (64.6%)	
Catholic	9 (8.7%)	3 (7.8%)	6 (9.2%)	
Jewish	1 (1.0%)	0 (0%)	1 (1.5%)	
Other	8 (7.8%)	3 (7.8%)	5 (1.0%)	
None/Agnostic	6 (5.8%)	1 (2.6%)	5 (1.0%)	
Missing	8 (7.7%)	2 (5.2%)	6 (9.2%)	
How religious				0.84
Not religious at all	16 (15.5%)	4 (11.7%)	12 (18.7%)	
slightly religious	13 (12.6%)	5 (14.7%)	8 (12.3%)	
Moderately religious	35 (34.0%)	12 (35.3%)	23 (35.4%)	
Very religious	35 (34.0%)	13 (38.2%)	22 (33.8%)	
How spiritual				< 0.01
Not spiritual at all	5 (4.9%)	0 (0%)	5 (7.8%)	
Slightly spiritual	8 (7.8%)	3 (8.8%)	5 (7.8%)	
Moderately spiritual	43 (41.7%)	9 (26.5%)	34 (53.1%)	
Very spiritual	42 (40.8%)	22 (64.7%)	20 (31.3%)	
Number of spiritual care providers				< 0.01
0	0	0	0	
1	28	15	13	
2	28	7	21	
3+	47	16	31	

[a] *t* tests (age) and χ^2 tests for differences between patient and caregivers.

Three investigators (L.H., T.D., S.W.) used a consensus coding process to categorize responses to the open-ended question. Investigators independently categorized responses within 1 of the 18 spiritual care activities, or as an additional type of spiritual care. They discussed coding disagreements until agreeing on final codes by consensus.

Finally, interviewers asked Likert-scaled questions about satisfaction and perceived value of spiritual care. Recipients of spiritual care rated satisfaction with care on a five-point Likert scale from very satisfied (5) to very unsatisfied (1). They also rated how valuable spiritual care was to help them meet spiritual needs, to find peace, and to make meaning during this time of illness, using a four-point Likert scale with responses ranging from "it got in the way" (1) to "it helped greatly (4)." Items were summed for a perceived value score ranging from 4–12.

Analysis

We used standard descriptive statistics to report who provided spiritual care, types of activities, and recipients' satisfaction with care. We used Pearson correlation coefficients to examine bivariate associations between satisfaction and perceived value of spiritual care, and the characteristics of the spiritual care providers and types of spiritual care. All analyses were conducted using SPSS software, Version 15 (SPSS Inc., Chicago, IL).

RESULTS

We identified 125 potentially eligible patients or family recipients of spiritual care. Of these, 103 (82%) agreed to participate, including 38 seriously ill patients and 65 family caregivers for seriously ill patients. (Table 1). Recipients' ages ranged from 34–98, and patients were significantly older than family caregivers (72.9 versus 61.1 years, $p < 0.001$). They had relatively high educational attainment with 45% achieving college graduation. One in five recipients screened positive for depression. Religious affiliation, when present, was predominantly Protestant (69%), and 14% of recipients described themselves as having no religious affiliation. One third of recipients described themselves as very religious, and 41% described themselves as very spiritual. All reported they had received some form of spiritual care, and half of these reported three or more people who provided them with spiritual care.

Providers and types of spiritual care

The 103 recipients of spiritual care reported 237 people provided this care (Table 2). Spiritual care providers visited frequently, and 63% shared the faith tradition of the recipient. Of the 237 spiritual care providers identified by recipients, 95 (41%) were family or friends, 38 (17%) were clergy, and 66 (29%) were health care providers. Fifteen recipients also named God or a higher power as one of their sources of spiritual care.

We next described the types of spiritual care activities named in answer to an open-ended question or the inventory of possible spiritual care activities (Table 3). Responses were grouped in four domains, as well as additional activities that did not fit within the four domains. Between 66%–78% of participants reported various types of spiritual care that helped with relationships with loved ones or God. Somewhat smaller percentages of participants reported types of spiritual care that helped with understanding self and illness (45%–73%). Spiritual care helped with specific religious or spiritual practices for 34%–66% of recipients. In response to the open-ended question about spiritual care activities, participants also reported help with in-

Table 2. Spiritual Care Providers

Characteristic	n = *237 (%)*
Age	
18–24	1 (0.4)
25–40	45 (19.7)
41–55	98 (43.0)
56–70	53 (23.2)
71–85	16 (7.0)
Not applicable ("God/higher power")	15 (6.6)
Race	
African American/Black	38 (18.4)
Non-Hispanic White	159 (77.2)
Other	9 (4.3)
Female	121 (52.0)
Shares your faith tradition	135 (62.8)
How often visit/talk	
Less than once a month or less	23 (10.8)
At least once monthly	11 (5.2)
At least once weekly	73 (34.4)
At least once a day or more	105 (49.5)
Relationship to patient	
Family or friends	95 (41.2)
Clergy	38 (16.6)
Health care provider	66 (28.8)
God/higher power	15 (6.6)
Other	15 (6.6)

Actual sample size ranges between 236 and 206 due to missing data and the exclusion "God/higher power" from age, race, and gender categories.

Table 3. Process of Spiritual Caregiving

Activities	n = *103 (%)*
RELATIONSHIP	
Help relationships with those that you love	74 (71.8)
Help peace with loved ones	80 (77.7)
Help relationship with God	68 (66.0)
Help you feel at peace with God	73 (70.9)
UNDERSTANDING	
Help you to review the story of your life	54 (52.4)
Help you to be more aware and mindful of your life	72 (69.9)
Help you resolve fears of death/dying	50 (48.5)
Help you resolve concerns about suffering	46 (44.7)
Help you have hope	71 (68.9)
Help you recognize the significance/value of your life	75 (72.8)
Help understand meaning of illness	54 (52.4)
COPING	
Help you have a sense of control over your life	72 (69.9)
Help you cope with your/patient's illness	90 (87.4)
PRACTICES	
Help you attend religious/spiritual services	35 (34.0)
Help you in religious/spiritual practices	53 (52.5)
Help you with your prayer	62 (61.4)
Help you to better understand your faith	59 (57.3)
Help you by asking others to pray for you	68 (66.0)
ADDITIONAL ACTIVITIES	
Help you with insight into the dying experience	20 (19.4)
Offer comfort	11 (10.7)
Offer intercessory prayer	4 (3.9)

sight into dying, comfort, and intercessory prayer. The most common type of spiritual care was help in coping with illness (87%), and the least common was intercessory prayer (4%).

Just over half (55%) of spiritual care recipients were very satisfied or somewhat satisfied with the care that they received (Table 4). Most recipients (72%) felt that the spiritual care they had experienced was very valuable to meet their spiritual care needs, but smaller percentages felt it was very valuable as a resource to find inner peace (54%), or to help them make meaning (52%). An overall score for perceived value was created by summing the Likert scale ratings of perceived value for meeting needs, inner peace, and meaning. The average score for perceived value of spiritual care was 10.2 (standard deviation [SD] 1.9) out of a possible score from 4 to 12. Patients and family caregivers did not differ significantly regarding their satisfaction with or perceived value or care. Satisfaction and perceived value were well correlated with one another ($r = 0.497$, $p < 0.001$).

Are providers and types of care associated with satisfaction with care?

In initial bivariate comparisons, most provider characteristics showed no correlation with the recipient's report of satisfaction and perceived value of spiritual care. Specifically, these outcomes did not differ by the spiritual care provider's age, race, gender, or frequency of visits, and did not differ if the provider was family or friend, clergy, or a health care provider. Recipients who screened positive for depression reported lower satisfaction with spiritual care ($r = -0.264$, $p = 0.008$) and lower perceived value of this care ($r = -0.259$, $p = 0.012$). Satisfaction tended to be lower if the spiritual care provider shared the recipient's faith tradition ($r = -0.138$, $p = 0.046$). We found that satisfaction with care was greater when spiritual care included helping with understanding ($r = 0.251$, $p = 0.001$) or helping to cope with illness ($r = 0.168$, $p = 0.012$). The perceived value of care was higher if spiritual care included help with understanding ($r =$

Table 4. Outcomes of Spiritual Care

Outcomes	n = *103*	*Patients* n = *38 (%)*	*Caregivers* n = *65 (%)*	p *value*[a]
Satisfaction				0.79
Very satisfied/Somewhat satisfied	57 (55.3)	20 (52.6)	37 (56.9)	
Neutral/Somewhat unsatisfied	31 (30.1)	13 (34.2)	18 (27.7)	
Very unsatisfied	12 (11.7)	4 (10.5)	8 (12.3)	
Value meeting spiritual needs				0.59
Very valuable	69 (67.0)	26 (68.4)	43 (66.2)	
Somewhat valuable	22 (21.3)	8 (21.1)	14 (21.5)	
Not valuable	3 (2.9)	0	3 (4.6)	
Worthless	2 (1.9)	1 (2.6)	1 (1.5)	
Help with inner peace				0.35
Helped greatly	52 (50.5)	21 (55.3)	31 (47.7)	
Helped somewhat	35 (34.0)	11 (28.9)	24 (36.9)	
Did not help	9 (8.7)	2 (5.3)	7 (10.8)	
It got in the way	1 (1.0)	1 (2.6)	0	
Help make meaning				0.16
Helped greatly	49 (47.6)	18 (47.4)	31 (47.7)	
Helped somewhat	33 (32.0)	15 (39.5)	18 (27.7)	
Did not help	13 (12.6)	2 (5.3)	11 (16.9)	
It got in the way	0 (0)	0	0	
Perceived value score (4–12)	10.4	10.0	10.35	0.53

[a]χ^2 tests were conducted for differences between patient and caregiver respondents; *t* test for difference between patient and caregiver perceived value score.

0.483, $p < 0.001$), spiritual care practices ($r = 0.460$, $p < 0.001$), relationships ($r = 0.371$, $p < 0.001$), or with coping with illness ($r = 0.273$, $p < 0.001$).

DISCUSSION

Patients and families, and now consensus practice guidelines, endorse the importance of care for religious and spiritual concerns when disease causes suffering and threatens life. Although prior research has helped illuminate the value of patients' own spiritual and religious beliefs in facing serious illness, the value of spiritual care from others has not been well defined. To our knowledge, this study provides the first empiric data on who provides spiritual care, what is provided, and how well it satisfies the needs of seriously ill patients and family caregivers.

Health care providers are increasingly called to assume responsibility for spiritual care, but their willingness and ability to do so is debated.[22–24] Our respondents reflected on the past several months spent in and out of hospital, and reported that spiritual care came from multiple sources. Surprisingly, family, friends, and health care providers were more commonly named as spiritual care providers than were clergy. Spiritual care activities were varied, but help with relationships and coping were more common than prayer, religious ritual, or services. These results suggest that seriously ill patients and their families have a holistic view of spiritual care, consistent with integrated models for the care of seriously ill patients.[7]

Characteristics of spiritual care providers were not linked to better outcomes, but some types of spiritual caregiving were correlated with greater satisfaction and perceived value. The finding that satisfaction with care was somewhat lower when provider and recipient shared the same faith tradition was unexpected. Patients and families may have higher expectations when spiritual care comes from someone within their faith community. This finding suggests that ecumenical spiritual care is possible, and can be as satisfying as direct care from within a faith community. Outcomes of spiritual care were modest, with only about half reporting they were very or somewhat satisfied with care. Given that measures of satisfaction with other aspects of healthcare are frequently positively skewed, these findings suggest that seriously ill patients and family caregivers have unmet spiritual needs.

As patients and families face serious illness, access to clergy and to faith communities diminishes. Strategies to meet the demand for spiritual care could include expanding the presence of clergy in healthcare. Alternatively, health care providers may have the potential to provide spiritual care. Given the existing pressures of health care delivery, these individuals

may require both training and dedicated time if spiritual care is valued for seriously ill and dying patients.

This research has several implications for the enhancement of spiritual care for seriously ill patients. First, role-based models of spiritual care, where an interdisciplinary care team member each attends to a specific care dimension, may need to be reconsidered.[25] Our data suggest that satisfaction with spiritual care is not related to who provides it. Second, interventions seeking to improve spiritual care need to address both facilitators and limits on of this type of care, such as having ample, unencumbered time. Simply taking a spiritual history may honor the patient's need to be seen as more than a physical being, and health care providers can learn this skill.[26] However, for patients with deep existential suffering, this level of attention may not be enough. Innovative forms of therapy are being developed and studied that attend to spiritual as well as emotional needs.[15–17]

This study must be considered in light of its limitations. First, we used predominantly structured interview questions. Qualitative, inductive approaches may explore more aspects of the spiritual care experience than our methods captured. To examine this potential, we have completed qualitative analysis of narrative interviews with health care providers named as spiritual caregivers in this study, to further explore the experience of spiritual caregiving by health care providers.[27] Future qualitative and quantitative research is needed to describe effective spiritual care and its outcomes.

The participants all came from a single site and all reported receiving some spiritual care. Despite a relatively high response rate, participants may represent a group to whom spiritual care is especially significant. Patients and caregivers from other cultural, regional, or educational backgrounds may respond differently. In addition, we combined patients and caregivers; while we did not find major differences between these subgroups, the number of patients included was small and may not adequately represent the patient experience. In spiritual care research, validated instruments are available to measure spirituality and religiosity, spiritual needs and religious practices. However, we could not identify any validated measures of the experience of spiritual care, or measures of the quality of this care as perceived by recipients. Therefore, our study measures are based on a conceptual framework, but are not standardized or validated tools.

Our study suggests that patients' and families' needs are only modestly satisfied by the spiritual care they experience. Before mandating spiritual care delivery, it would be useful to study how best to meet these expressed needs. Our findings support the importance of spiritual care to patients and family caregivers in the face of serious illness, and provide some guidance for how it can be improved. Future studies should test spiritual care interventions against defined outcomes, such as satisfaction with care and perceived value of care to promote a sense of peace or meaning in the face of serious illness.

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Address reprint requests to:
Laura C. Hanson, M.D.
Division of Geriatric Medicine
University of North Carolina
CB 7550
Chapel Hill, NC 27599

E-mail: lhanson@med.unc.edu