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ORIGINAL ARTICLE

Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients

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Abstract
Purpose Spiritual care is an important part of healthcare, especially when facing the crisis of advanced cancer. Do oncology inpatients receive spiritual care consistent with their needs? When inconsistent, are there deleterious effects on patient outcomes?
Methods Patients with advanced cancer (N=150) were surveyed during their inpatient stay at a southeastern medical center using validated instruments documenting spirituality, quality of life, mood, and satisfaction with care. Relationships between the receipt of less spiritual care than desired and patient outcomes were examined.
Results Almost all patients had spiritual needs (91%) and the majority desired and received spiritual care from their healthcare providers (67%; 68%), religious community (78%; 73%), and hospital chaplain (45%; 36%). However, a significant subset received less spiritual care than desired from their healthcare providers (17%), religious community (11%), and chaplain (40%); in absolute terms, the number who received less care than desired from one or more sources was substantial (42 of 150). Attention to spiritual care would improve satisfaction with care while hospitalized for 35% of patients. Patients who received less spiritual care than desired reported more depressive symptoms [adjusted β (SE)=1.2 (0.47), p=0.013] and less meaning and peace [adjusted β (SE)=−2.37 (1.15), p=0.042].
Conclusions A substantial minority of patients did not receive the spiritual care they desired while hospitalized. When spiritual needs are not met, patients are at risk of depression and reduced sense of spiritual meaning and peace. Spiritual care should be matched to cancer patients' needs.

Keywords Spiritual needs · Advanced cancer patients · Spiritual care · Quality of life · Depression · Inpatient

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Spirituality plays an important and relevant role in the provision and receipt of healthcare [1], particularly at the end of life. A growing body of research shows that many patients want their physicians to discuss spiritual issues with them [2, 3]. Even among nonreligious patients, 45% want their physician to make a polite inquiry [4], and there is evidence that even if patients don't want their spiritual needs met, meeting those needs is associated with greater satisfaction with care [5]. Major healthcare organizations now strongly recommend, and some require, that their members assess spirituality and provide spiritually sensitive care [6–8]; failing to do so today does not meet the standard of care.

Most advanced cancer patients have spiritual needs [2, 3] and report that religion becomes more important to them after diagnosis [9]. Support of spiritual needs in outpatient medical settings is associated with greater satisfaction and perceived quality of care [2], less depression [10], higher quality of life [9, 10], greater hospice use [11], and decreased medical care costs [12]. Several studies have documented deficits in spiritual care provision for advanced cancer patients. For example, in a sample of 369 cancer outpatients, 73% reported having at least one spiritual need; of these patients, 18% reported that their spiritual needs were not being met [2]. In another sample of 230 advanced cancer outpatients, 72% reported that the medical system supported their spiritual needs minimally or not at all [9].

Hospitalization can be a time of intense distress. Hospitalized advanced cancer patients frequently have acute physical needs, poor functional status, and substantial emotional distress. It follows that support of advanced cancer patients' holistic needs, including their unique spiritual needs, would be important. But, there is a paucity of information on the importance of spiritual care for cancer inpatients and on how spiritual care influences quality of life, well-being, and satisfaction with healthcare. Available data from 2,768 general medicine inpatients demonstrated that 41% wanted a discussion about spiritual concerns but that the need was not met in one half of these patients [5].

To advance spiritual support for people with cancer, it follows that we should distinguish between patients who want their medical team to provide spiritual care and those who do not, as well as to identify patients who are not receiving the extent of spiritual care they desire. What if we do not? Does discrepancy between the desire for and receipt of spiritual care from the medical team adversely affect patient-centered outcomes among inpatients with advanced cancer? To answer this question, we surveyed a sample of culturally diverse hospitalized advanced cancer patients to examine: (1) the proportion who do not receive the spiritual care that they desire and (2) the relationship between receipt of less spiritual care than desired and patient-centered outcomes. We hypothesized that patients who receive less spiritual care than desired will have lower quality of life and spiritual well-being and more depressive symptoms.

Methods

Participants

Potential participants were recruited during 2008–2010 from the malignant hematology and solid tumor oncology inpatient units at Duke University Medical Center. Consenting participants were: (1) adults (age ≥18) diagnosed with advanced cancer of any subtype (stage III or IV solid tumors or lymphoma, or acute leukemia), for whom the treating physician or midlevel provider indicated that he/she would not be surprised if the patient were to die of their cancer within the next 12 months [13]; (2) receiving care from the hematology/oncology inpatient service; (3) cognitively capable of completing questionnaires; and (4) fluent in English. The study was approved by the Duke University Health System Institutional Review Board.

Measures

Clinical information was extracted from the patients' medical record. Participants completed the following assessments:

Demographic information Participants reported age, gender, race, marital status, education level, religious affiliation, location of residence, and cancer diagnosis.

Spiritual well-being The Functional Assessment of Chronic Illness Therapy—Spiritual Well-being (FACIT-Sp) [14] measures the extent to which medical patients experienced aspects of spiritual well-being in the past week (0="not at all" to 4="very much") and consists of two empirically validated subscales: The meaning and peace subscale made up of eight items that measure a sense of meaning, purpose, harmony, and extent to which patients draw comfort from themselves. The faith subscale consists of four items that assess the extent to which patients find strength and comfort in their religious faith and rely on their faith to cope.

Spiritual needs and spiritual care Eleven items were developed for this study to assess the degree to which patients desired and received spiritual care from their medical team, religious community, and hospital chaplain. One item asked "Would attention to your spirituality and spiritual care improve your satisfaction with care at Duke University Hospital?" After the first seven patients were enrolled, we added eight questions to assess specific spiritual needs, adapted from the spiritual needs assessment scale [15]. All items were rated on a five-point scale (0="not at all" and 5="to the largest extent possible").

Quality of life The Functional Assessment of Cancer Therapy-General (FACT-G) [16] comprises 27 questions that assess well-being in four domains: physical, functional, emotional, and social. Both the total score and the individual subscale scores have demonstrated good internal consistency and reliability. The social well-being FACT-G subscale was not used in analyses because of a ceiling effect in the responses.

Depressive symptoms The Center for Epidemiological Studies Depression (CES-D) Symptoms Index Short Form, a

Table 1 Characteristics of sample population (N=150)

Characteristic	Number	Percent
Gender		
Female	69	46
Male	81	54
Age at consent		
Age ≤65 years	90	60
Age >65 years	60	40
Mean (SD)	58.6 (14.2)	
Race		
Black or African American	26	17
Caucasian	110	73
Other	12	8
Educational status		
<Bachelor's degree	81	54
Bachelor's degree and above	60	40
Marital status		
Married	112	75
Not married	37	25
Location[a]		
Local	47	31
Not local	91	61
Religion		
Catholic	16	11
Jewish	2	1
Protestant	118	79
Other	8	5
None	6	4
Cancer diagnosis		
Leukemia/myeloma	68	45
Lymphoma	26	17
Other	47	31
AKPS (%), (n=100)[b]		
20–40	26	17
50–70	35	23
80–100	39	26
Median	70	
Days hospitalized (n=108)		
Mean (SD)	9.1 (11.1)	
FACT-G emotional well-being (n=143)[c]		
Mean (SD)	17.1 (5.0)	
FACT-G functional well-being (n=139)		
Mean (SD)	13.2 (6.1)	
FACT-G physical well-being (n=144)		
Mean (SD)	14.0 (6.5)	
FACT-G total (n=141)		
Mean (SD)	68.4 (14.9)	
FACIT-Sp faith (n=139)[d]		
Mean (SD)	13.9 (3.1)	
FACIT-Sp meaning/peace (n=143)		
Mean (SD)	25.3 (5.5)	
FACIT-Sp total (n=143)		
Mean (SD)	39.2 (7.2)	
CES-D: depressive symptoms (n=140)[e]		
Mean (SD)	5.7 (2.5)	

The total N may not sum to 150 patients for specific characteristics due to missing data, unless otherwise noted. Higher scores indicate better QOL for FACT-G and FACIT-Sp and greater depressive symptoms for CES-D

SD standard deviation, *AKPS* Australian-modified Karnofsky Performance Status, *FACT* Functional Assessment of Cancer Therapy-General; *FACIT-Sp* Functional Assessment of Chronic Illness Therapy—Spiritual Well-being; *CES-D* Center for Epidemiological Studies—Depression Scale

[a] Local was defined as zip codes located in Durham, NC and its bordering counties

[b] The AKPS [22] is a clinician's assessment of how well a patient can function and perform daily activities. It is an updated version of the well-known Karnofsky scale that incorporates language appropriate for contemporary medical practice. Scores range from 100="normal, no complaints or evidence of disease" to 0="dead." This measure was added after the first 50 patients were enrolled to provide an additional measure of physical functioning

[c] For FACT scales a meaningful clinical difference is defined as a value greater than 0.5 SD above or below the mean of the norm. The study population has comparable scores of FACT emotional well-being when compared to the general population and to cancer patient populations. The scores for physical and functional well-being for the study population are clinically different (i.e., significantly lower), demonstrating that this sample is less healthy and more disabled compared to both the general population and the cancer patient population [23]

[d] For FACIT-Sp scales a meaningful clinical difference is defined as a value greater than 0.5 SD above or below the mean of the norm. FACIT-Sp scores are comparable to the general population and cancer patient population [14]

[e] There is a high degree of depressive symptoms in the study population based on cutoff point of 4 [17]

five-item self-report scale, is a brief version of commonly used 20-item CES-D that assesses depressive feelings and behaviors over the last week. The briefer form assesses the same symptoms and has similar sensitivity and specificity as does the longer scale [17].

Statistical analyses

Descriptive statistics (i.e., means, medians, and standard deviations for continuous data, and frequency counts and proportions for categorical data) were reported as appropriate. Linear regression was used to assess the relationship between receiving less overall spiritual care from one or more sources (i.e. healthcare professionals, religious community, or hospital chaplain) than desired and quality of life (FACT-G and subscales), depressive

symptoms (total CES-D score), and spiritual well-being (FACIT-Sp and subscales). The receipt of less spiritual care than desired from each source was defined as a two- or more point difference on the five-point scale anchored between desired and received. All regression models were adjusted for the following covariates: gender, race (non-white vs. white), age (>65 vs. ≤65 years), marital status (married vs. not married), education (bachelor's+ vs. <bachelor's), disease type (two indicator variables accounting for lymphoma, leukemia/myeloma, and other), and location relative to Durham, North Carolina (local vs. not local). Local was defined as zip codes located in Durham and its bordering counties. Length of hospital stay and Australian-modified Karnofsky Performance Status were not considered as covariates due to missing data. A two-sided significance level of $p<0.05$ was used for all analyses. SAS version 9.2 (SAS Institute, Cary, NC) was used.

Results

Participants

Among the 268 patients eligible for participation, 118 declined enrollment and 150 were consented to participate. The main reasons given for not participating were "not interested" ($n=42$), "too ill" ($n=33$), reason not provided ($n=35$), and "other" ($n=8$). Potential differences between consenters and nonconsenters were not reported due to unavailable demographic data for nonconsenters. Participants were 54% male, on average 59 [standard deviation (SD), 14] years of age, 25% non-Caucasian, married (75%), and primarily Protestant (79%). Median performance status was 70% (see Table 1).

Spiritual needs

Eighty-five percent of patients stated that spirituality played a "large to the largest extent possible" role in their overall health and recovery. Thirty-five percent of patients reported that attention to their spirituality and spiritual care would improve their satisfaction with care at Duke University Hospital. Of the 143 patients queried about spiritual needs, 130 (91%) indicated having one or more spiritual needs (median=4). The percentage of patients who endorsed experiencing each of the eight specific spiritual needs is displayed in Table 2.

Spiritual care desire vs. spiritual care received

Two thirds of patients (67%) reported that they had a moderate or greater desire for their medical team to support their spiritual needs and 68% reported that their medical team had provided spiritual care to this extent. The majority of patients (78%) reported that they had a moderate or greater desire for their religious community to support their spiritual needs and 73% reported that their religious community had provided spiritual care to this extent. Almost half (45%) of patients reported that a visit by a hospital chaplain would be helpful to a moderate or greater extent during their hospitalization; 36% reported having received a visit by a chaplain (see Table 3).

We assessed the consistency between desired and received spiritual care. We considered a discrepancy between desired and received to be a two- or more point difference between reports for these variables on a five-point scale [e.g., desire

Table 2 Summary of spiritual needs ($N=143$)

Spiritual need questions	Reported as a spiritual need[a]			
	No		Yes	
	Number	Percent	Number	Percent
At any time during your hospital stay, have you wanted a connection with a higher power?	15	10	116	81
At any time during your hospital stay, have you wanted to address concerns about life after death?	103	72	31	22
At any time during your hospital stay, have you wanted to forgive yourself or others?	63	44	71	50
At any time during your hospital stay, have you wanted to have someone pray with or for you?	37	26	97	68
At any time during your hospital stay, have you wanted to make sense of why this happened to you?	84	59	51	36
At any time during your hospital stay, have you wanted to participate in religious or spiritual services?	80	56	54	38
At any time during your hospital stay, have you wanted to perform religious or spiritual rituals?	107	75	27	19
At any time during your hospital stay, have you wanted to read spiritual or religious material or watch spiritual or religious programs on TV?	55	38	81	57

After the first seven patients were enrolled, these eight questions were added to assess specific spiritual needs. Thus, the total N is 143 instead of 150. The total N may not sum to 143 patients for specific questions due to missing data

[a] A spiritual need was defined as a response of 3 or higher on a five-point scale (i.e., moderate extent and above)

Table 3 Summary of desired and received spiritual care

Item	Number	Percent
During your stay at the hospital, to what extent do you want your healthcare team to support and address your spiritual needs?[a]	$n=143$	
Not at all	24	17
To a small extent	21	15
To a moderate extent	31	22
To a large extent	33	23
To the largest extent possible	31	22
During your hospitalization, to what degree has your healthcare team (e.g., doctors, nurses) supported and addressed your spiritual needs?[a]	$n=143$	
Not at all	26	18
To a small extent	17	12
To a moderate extent	38	27
To a large extent	25	17
To the largest extent possible	35	24
Received less spiritual care than desired from healthcare team[b]		
No	79	83
Yes	16	17
During your stay at the hospital, to what extent do you want your religious community to care for you?		
Not at all	16	11
To a small extent	10	7
To a moderate extent	36	24
To a large extent	36	24
To the largest extent possible	45	30
During your hospitalization, to what extent have you been cared for by your religious community (e.g., clergy, congregation members)?		
Not at all	20	13
To a small extent	16	11
To a moderate extent	31	21
To a large extent	41	27
To the largest extent possible	38	25
Received less spiritual care than desired from religious community[b]		
No	104	89
Yes	13	11
Would a visit by a hospital chaplain be helpful to you during your hospitalization?		
Not at all	50	33
To a small extent	23	15
To a moderate extent	33	22
To a large extent	18	12
To the largest extent possible	17	11
Have you been visited by a hospital chaplain during your stay at the hospital?		
No	89	59
Yes	54	36
Do not know	2	1
Received less spiritual care than desired from hospital chaplain[b]		
No	41	60
Yes	27	40
Received less overall spiritual care than desired from one or more sources (i.e., healthcare team, religious community, or chaplain)		
No	108	72
Yes	42	28

The total *N* may not sum to 150 patients for specific characteristics due to missing data, unless otherwise noted

[a] This question was revised after the first seven patients were enrolled. Thus, the total sample size is 143 instead of 150. The total *N* may not sum to 143 patients due to missing data

[b] The total *N* is based upon the number of patients that reported desire for spiritual care to a moderate extent and above

care to largest extent possible (score of "5") but received care to a moderate extent ("3"), small extent ("2"), or not at all ("1")]. Of the patients that had a moderate or greater desire for the healthcare team to support their spiritual needs, 17% (16 of 95) received less than the care they desired. Of the patients that had moderate or greater desire for their religious community to support their spiritual needs, 11% (13 of 117) received less than the care they desired. Of patients that thought it would be helpful to be visited by a chaplain, 40% (27 of 68) had not received such a visit (see Table 3).

Less than desired overall spiritual care and well-being outcomes

We explored the relationship between study outcomes and receiving less spiritual care than desired. Twenty-eight percent (42 of 150) received less overall spiritual care than desired from one or more sources (i.e., medical team, religious community, or chaplain). Linear regression analyses revealed that patients who received less overall spiritual care than desired had greater depressive symptoms [adjusted β (standard error, SE)=1.2 (0.47), $p=0.013$] and lower meaning and peace scores [adjusted β (SE)=−2.37 (1.15), $p=0.042$] (Table 4).

Discussion

The majority of advanced cancer patients have spiritual needs while hospitalized, believe that spirituality plays a major role in their health and recovery, and desire spiritual care from their healthcare team, religious community, and/or hospital chaplain. A high proportion of the patients desiring spiritual support received it. Nonetheless, there was still a

Table 4 Linear regression models for the association between receipt of less overall spiritual care than desired and QOL, depressive symptoms, and spiritual well-being

Outcome	Univariate analysis				Multivariate analysis[a]			
	Number	β	SE	p value	Number	β	SE	p value
CES-D: depressive symptoms	140	0.92	0.45	0.044[b]	116	1.2	0.47	0.013[b]
FACIT-Sp faith	139	0.30	0.58	0.603	116	−0.25	0.65	0.706
FACIT-Sp meaning/peace	143	−2.38	0.99	0.018[b]	118	−2.37	1.15	0.042[b]
FACIT-Sp total	143	−2.04	1.32	0.124	118	−2.66	1.51	0.082
FACT-G emotional well-being	143	−1.54	0.92	0.097	119	−1.49	1.07	0.167
FACT-G functional well-being	139	−1.25	1.16	0.282	116	−0.23	1.36	0.864
FACT-G physical well-being	144	−0.43	1.20	0.724	118	−0.33	1.33	0.804
FACT-G total QOL	141	−4.11	2.80	0.144	118	−2.22	3.06	0.469

Sample size varied because of missing data. Higher scores indicate better QOL for FACT-G and FACIT-Sp and greater depressive symptoms for CES-D

AKPS Australian-modified Karnofsky Performance Status; *FACT* Functional Assessment of Cancer Therapy-General; *FACIT-Sp* Functional Assessment of Chronic Illness Therapy—Spiritual Well-being; *CES-D* Center for Epidemiological Studies—Depression Scale; *QOL* quality of life

[a] Multivariate analysis performed with all variables entered simultaneously into the model. Estimates were adjusted for gender, race (non-white, white), age (>65 years, ≤65 years), marital status (married, not married), education (bachelor's+, <bachelor's), disease type (lymphoma, leukemia/myeloma, other), and location relative to Durham, NC (local, not local).

[b] Statistically significant; a two-sided p value <0.05 was considered statistically significant

substantial group of individuals who desired more spiritual care than they received while hospitalized. People who received less spiritual care than they desired were at significantly greater risk of depressive symptoms and lower sense of spiritual well-being, defined as poorer sense of purpose in life, meaning and peace. In addition, 35% stated that attention to their spirituality and spiritual needs would improve their satisfaction with care while hospitalized.

Almost all patients reported having at least one spiritual need (91%); the most frequent were a desire for a connection with a higher power (81%) and a desire to have someone pray with them (68%). The number of patients who endorsed having spiritual needs was higher than previous studies examining spiritual needs among nonhospitalized advanced cancer patients [2, 3]; this may reflect the distress of hospitalization and advanced care or some other sociocultural evolution. A substantially greater percent of participants reported receiving spiritual support from their inpatient healthcare team (68%) compared to previous studies. This may reflect that spiritual care is less prevalent for outpatients (see [9]) or general medicine inpatients (see [5]), or something unique about the patients and/or healthcare providers at Duke Medical Center. Prior research has shown that inpatient status and illness severity predict greater patient desire and greater physician provision of spiritual care [18].

Cultural differences may also explain the contrast, as our sample resides in the Southeastern United States, a region that is historically known to be more religious, whereas Williams and colleagues' [5] sample resided in Chicago and the majority of Balboni and colleagues' [9] sample resided in the Northeast. Support for this hypothesis comes from a recent report by Balboni and colleagues [12] whose sample included additional cancer patients from the South (i.e., Texas) to the sample in their earlier report [9]. In this larger sample, patients residing in the South reported receiving more spiritual care than did those in the Northeast, and 55% of the total sample endorsed receiving spiritual care from a moderate to largest extent possible, a percentage that is closer to that of the current study (68%). It may be that patients in the South desire more spiritual care and consequently receive it. Medical professionals in the South may also be more likely to see spiritual care as their responsibility than do those in the Northeast. For example, patients in our study received fewer visits from chaplains than did patients in Balboni and colleagues' study [9] (36% vs. 52%), but more spiritual care from the medical team (68% vs. 28%). In Williams and colleagues' study [5], only 8% of patients had a spirituality-focused discussion with a physician. Overall, these observations support an approach to spiritual care that is tailored to patient needs, culturally appropriate, and aligned with personal and regional expectations.

Despite the fact that more patients in this sample reported receiving spiritual care from their medical team, there was a subset of patients who had a moderate or greater desire for spiritual care who received less care than they desired from their healthcare team (17%), religious community, (11%), or hospital chaplain (40%) while hospitalized. These results are similar to those of Williams and colleagues [5] who found that nearly half of general medicine inpatients who

desired a discussion about spiritual concerns while hospitalized did not have such a discussion. Notably, patients in our sample of hospitalized advanced cancer patients who received less spiritual care than they desired from their healthcare team, religious community, or chaplain reported greater depressive symptoms and lower levels of spiritual well-being. These findings are consistent with previous research revealing that spiritual concerns and lack of meaning and peace are associated with poorer psychological well-being and quality of life among cancer patients [3, 11, 19]. This is the first study to examine depression and spiritual care received. This finding has important clinical implications given the established relationship between depression, functional disability, and mortality, particularly among the medical patients [20]. Moreover, the potential to reduce depressive symptoms through the provision of spiritual support is in line with the Joint Commission on Accreditation of Healthcare Organizations' regulations [7] requiring that all hospitalized patients receive a spiritual assessment, as well as national and international palliative care guidelines [8].

Limitations of this study include the cross-sectional design, which precludes statements of causality. Second, we intentionally chose to use a short measure of depressive symptoms because of the emotional and physical limitations of hospitalized advanced cancer patients. Previous studies with advanced cancer patients have revealed that data collected are most accurate when brief assessment batteries are used, containing only the most critical elements [21]. However, it remains to be seen how depression and other psychological disorders as defined by the DSM-IV are associated with a discrepancy between desired and received spiritual care. Third, our measure of spiritual care preferences and needs was not validated, although 8 of the 19 questions were drawn from a previously validated measure [15]. Fourth, our sample was highly religious, predominately Protestant, and drawn from one location in the South limiting the generalizability of the results. Finally, because of the sample size and high prevalence of matched spiritual care to desire for individual sources of spiritual care, we could not examine the association of discrepant desired and received spiritual care for specific sources of care.

This is the first study to provide a snapshot of the relationships between spiritual care needs and patient outcomes among hospitalized advanced cancer patients. What are the implications for clinical practice? Spiritual care matters to patients. It is clearly important to identify patients with a discrepancy between the amounts of spiritual care and support that they desire and that which we, as healthcare professionals, provide or facilitate. Not all spiritual care needs come from the medical team; the religious community and chaplains were important sources of support for these patients and the healthcare system can facilitate access. When needs are not met, patients are at risk for depression and reduced sense of spiritual meaning and peace. Providing patients with the spiritual care they desire may be one way we can improve satisfaction with care for a number of hospitalized advanced cancer patients. Larger studies, from diverse geographic areas and populations, are needed, especially to help us understand the overall implications of these findings globally on patient suffering, quality of life, adaptive psychological adjustment style, and mortality [19, 20]. And, development and provision of spiritually oriented interventions that match patients' spiritual care desires and needs to care provided may be an important next step in advanced cancer patient care.

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