

Palliative care and spiritual well-being in lung cancer patients and family caregivers

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Abstract

Background: Spiritual well-being is an important dimension of quality of life (QOL) and is a core component of quality oncology and palliative care. In this analysis, we aimed to describe spiritual well-being outcomes in a National Cancer Institute (NCI)-supported Program Project that tested the effectiveness of an interdisciplinary palliative care intervention in lung cancer patients and their family caregivers (FCGs).

Methods: Patients undergoing treatments for NSCLC and their FCGs were enrolled in a prospective, quasi-experimental study. Patients and FCGs in the intervention group were presented at interdisciplinary care meetings and received four educational sessions that included one session focused on spiritual well-being. Spiritual well-being for patients was measured using the FACIT-Sp-12, and FCG spiritual well-being was measured using the COH-QOL-FCG spiritual well-being subscale. Multivariate analysis of covariance was undertaken for subscale and item scores at 12 weeks, controlling for baseline, by religious affiliations (yes or no) and group assignment.

Results: Religiously affiliated patients reported better scores in the Faith subscale and items on finding strength and comfort in faith and spiritual beliefs compared to non-affiliated patients. Non-affiliated patients had better scores for feeling a sense of harmony within oneself. By group, patients who received the intervention had significantly better scores for the Meaning/Peace subscale.

Conclusions: Our findings support the multidimensionality of spiritual well-being that includes constructs such as meaning and faith for lung cancer patients and FCGs with or without religious affiliations. Palliative care interventions should include content that targets the spiritual needs of both patients and FCGs.

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Background

A diagnosis of lung cancer has a profound impact on the quality of life (QOL) of patients and FCGs. QOL is a multidimensional concept that addresses the impact of traumatic events such as cancer on aspects related to physical, functional, psychological, social, and spiritual well-being. The last two decades have seen a growing body of literature that describes the importance of religion/spirituality in cancer research and the clinical care of cancer patients. Clinical practice guidelines, such as those developed through the National Consensus Project (NCP) for Quality Palliative Care [1] and National Quality Forum [2], have subsequently endorsed the belief that spiritual care is a fundamental component of quality cancer care from diagnosis to the end of life [3]. The National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines identifies spiritual distress as a key element of comprehensive psychological distress screening [4].

Despite the growing recognition of its importance in oncology, religion/spirituality is perhaps the least understood and most understudied QOL domain. The lack of clear definitions and difficulties in reliably measuring the concept are major barriers to the continued growth of religion/spirituality research in oncology. In general, it is now widely accepted that the concept of religion/spirituality is a broader construct that involves many dimensions, including beliefs and practices associated with a religious organization, experiences, sense of purpose and connectedness to the moment, self, the sacred, and others [5–9]. There are multiple definitions of religion/spirituality, but the term spirituality generally refers to a connection with a larger reality that provides meaning to life and can be experienced through private and public devotions or through meditation, nature, or art [10]. The NCP defines spirituality as the ‘aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their

connectedness to the moment, to self, to others, to nature, and to the significant or sacred.' [1] Individuals diagnosed with cancer often turn to religion/spirituality to cope with their illness and its treatments [5,11–13]. Approximately 86% to 91% of patients with advanced cancer have spiritual needs, and these are often defined as spiritual struggles, spiritual seeking (e.g. seeking forgiveness), and the search for purpose and meaning in life following diagnosis [14,15]. Spirituality and improved spiritual well-being are correlated with better overall QOL, psychosocial functioning, and cancer-related anxiety and depression [8,10,11,16–18]. Unmet spiritual needs are associated with diminished QOL, less hospice utilization, and higher healthcare costs in terminally ill cancer patients [15,17,19,20]. Spiritual distress and negative religious coping (e.g. feelings of being abandoned by God and anger at God) can also negatively impact QOL and psychological adjustment to cancer [15,21]. Spiritual needs are also common in family caregivers (FCGs) of cancer patients, and include similar aspects such as finding purpose and meaning in life [22]. The burdens and demands of caring for a spouse, family member, or friend with cancer often provoke existential and spiritual concerns. FCGs who report the ability to maintain faith and derive meaning in cancer caregiving experience less caregiver burden and report better psychosocial functioning [23,24]. FCGs who report unmet spiritual needs and increased spiritual pain experience more psychological distress and QOL issues [25].

The research that exists related to spirituality in lung cancer patients and FCGs is sparse. In a prospective 10-year cohort of lung cancer survivors, spiritual well-being was associated with overall QOL, psychosocial functioning, and ability to perform roles [26–28]. Although spiritual well-being was not prognostic, current smokers reported the lowest spiritual well-being compared to never and former smokers [26]. Heightened psychological and spiritual distress is common at four key transitions for lung cancer patients: diagnosis, discharge after treatment, disease progression, and end of life [29,30]. Taken together, these studies provide preliminary insight into the importance of religion/spirituality for lung cancer patients and FCGs, but little is known about the differences in spiritual well-being based on self-reported affiliations with religious organizations.

The primary purpose of this analysis was to describe spiritual well-being outcomes in a National Cancer Institute (NCI)-supported Program Project that tested the effectiveness of an interdisciplinary palliative care intervention in lung cancer patients and their FCGs. The Program Project supported the simultaneous testing of the intervention for both patients and FCGs. For this analysis, we aimed to answer the following questions:

1. What is the spiritual well-being of lung cancer patients and FCGs?
2. Are there differences in spiritual well-being outcomes for patients and FCGs based on religious affiliations?
3. Are there differences in spiritual well-being outcomes for patients and FCGs by group (usual care versus intervention)?

Methods

Study design

This NCI-supported Program Project was a two-group, prospective sequential, quasi-experimental trial with a tandem enrollment design where patients and FCGs were enrolled into the usual care group first, followed by enrollment in the intervention group. Patients and FCGs were enrolled simultaneously, with FCG enrollment occurring at the time a matching patient was consented. This study design was selected, as opposed to a randomized design, to minimize the potential risk of contaminating the usual care group within the same institution, resulting in potential confounding effects on treatment outcomes. All participants completed written informed consent prior to enrollment. Participants in the usual care group were enrolled between November 2009 and December 2010, and intervention group enrollment occurred between July 2011 and August 2014. Data collection ended in September 2014. All study protocols and procedures were approved by the institutional review board. This paper presents spiritual well-being findings for patients and FCGs only.

Sample and setting

Patients with a diagnosis of stage I–IV non-small cell lung cancer (NSCLC) were invited by their treating physician to participate in the study. Upon enrollment, patients were asked to identify a FCG who might be willing to participate. For the purposes of this study, a FCG refers to either a family member or friend identified by the patient as being the primary caregiver. Written informed consents was obtained for both patients and FCGs. We included patients who fit the following eligibility criteria: (a) pathologically confirmed stage I–IV NSCLC; (b) scheduled to undergo treatments; and (c) ability to read and understand English. FCGs were eligible if they were 21 years or older and had a matching patient enrolled in the study. The study was conducted at one NCI-designated comprehensive cancer center located in Southern California.

Intervention

The interdisciplinary palliative care intervention for this study integrated key recommendations from the National

Consensus Project's Clinical Practice Guidelines for Palliative Care [31] and consisted of three key components. First, a comprehensive baseline QOL assessment for both patients and FCGs was completed by a nurse using validated measures. Spiritual well-being was an integral component of the assessment. Results from the assessments were then transferred to a personalized palliative care plan, which included a spiritual well-being section. Second, guided by the palliative care plan, patients and FCGs were presented at weekly interdisciplinary care meetings. The team meetings were attended by nurses, palliative medicine clinicians, thoracic surgeons, medical oncologists, a geriatric oncologist, pulmonologist, social worker, chaplain, dietitian, physical therapist, and key members of the research team. Recommendations were made on how to support both patients and FCGs spiritually. For patients, these recommendations included referrals to chaplaincy and other supportive care services. For FCGs, supportive care referrals were recommended for services such as chaplaincy and available community resources. Overall, a total of 139 interdisciplinary care meetings were conducted between July 2011 and August 2014, with each case presentation lasting approximately 15–20 min. FCGs and patients in the usual care group were allowed to access all supportive and palliative care services while on study.

The final component of the intervention involved the provision of four patient and FCG educational sessions. Separate sessions were conducted for patients and FCGs, and included a session focused exclusively on spiritual well-being. The educational sessions were administered by two advanced practice nurses who were assigned to work exclusively with the patient or the FCG. All APNs received extensive training on delivering the educational session content, and were monitored by the PI and research team. Participants were given an educational manual containing content organized by the QOL domains, and the manual was used to guide the educational sessions. At the beginning of the sessions, participants were presented with a list of common QOL topics, and were given the opportunity to select the topics that they were interested in discussing. This provided for tailoring of the content to personalized needs and preferences. The APNs then discussed each of the selected topics, and this included topic definitions, tips on how to cope with spiritual well-being issues, and supportive care services that can help. Spiritual well-being topics included the following: hope, inner strength, uncertainty, purpose and meaning in life, positive changes, redefining self and priorities, and spirituality/religiosity. On average, the spiritual well-being sessions lasted between 25 and 32 min. The top three spiritual well-being topics selected by patients for discussion included hope (72%), inner strength (64%), and uncertainty (55%). For FCGs, the most frequently

selected topics included purpose and meaning in life (54%), hope (49%), and redefining self and priorities (39%).

Outcome measures

Patient spiritual well-being was assessed using the 12-item Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp-12). Using a 5-point Likert scale, the tool measures a sense of meaning and peace and also assesses the role of faith in illness. The Meaning/Peace Subscale consists of eight items that measures existential well-being, and the Faith Subscale consists of four items that measures religious well-being. Total score ranges from 0 to 48, and a higher score indicates better spiritual well-being. Psychometric properties of the FACIT-Sp-12 were tested in a sample containing 1,617 subjects of whom the majority had a diagnosis of early stage and metastatic cancer (83.1%) [32]. Approximately 20% of subjects in this large sample were lung cancer patients. Reliability was established through internal consistency coefficients, with alpha coefficients of .81 to .88 for the total score and subscales [32].

Spiritual well-being for FCGs was assessed through the Spiritual Well-Being subscale of the City of Hope FCG QOL Tool (COH-QOL-FCG). This is a 37-item instrument that measures FCG QOL in the physical, psychological, social, and spiritual well-being domains. The spiritual well-being subscale contains 7 items with questions on support from religious activities, support for personal spiritual activities, uncertainty, positive changes in life, purpose/mission in life, hope, and overall spiritual well-being. All items are rated on a 1–10 scale, with higher scores representing worse QOL. The test-retest reliability was $r = .89$, and internal consistency was $\alpha = .69$ [33].

Statistical analysis

Data processing included scanning demographic and outcome measures and importing tracking data from an Access database. Data were analyzed using the Statistical Package for the Social Sciences, v. 21. (IBM Corp. Released 2012. IBM SPSS Statistics for Windows, Version 21.0. Armonk, NY: IBM Corp.) All results described herein are based on an intention to treat analysis. Consented patients and FCGs who completed their baseline measurement were included for analysis ($N = 475$ for patients; $N = 354$ for FCGs). After auditing the data for accuracy, data were matched by ID, and missing data were imputed using the SPSS Missing Values Analysis (MVA) procedure and the Estimation and Maximization (EM) method. Missing data for patients who died and FCGs whose patients died while on study ($N = 24$) were not imputed, as they were discontinued from the study. Selected demographic data for each data source (patients and FCGs) were separately compared by group (usual care vs. intervention) using contingency table analysis and the

chi square statistic, or Student's t-test, depending on level of measurement. Descriptive statistics were computed on baseline and 12-week (the primary end-point of the studies) spiritual QOL subscales and selected individual item ratings for both patients and FCGs. Spiritual well-being and its item components were then tested for significant differences by religious affiliation (yes or no) using Multivariate Analysis of Covariance (MANCOVA) controlling for baseline values. Significant differences by group (usual care versus intervention) was also tested using MANCOVAs. The multivariate approach was selected because we wanted to examine both individual items and subscales of the

FACIT spirituality scale. Therefore we needed a method that controlled for inflation of alpha because of multiple testing of potentially correlated items and subscales. Only if the multivariate F ratio for Pillai's Trace was significant did we report the significance of univariate results for individual items and subscales.

Results

A total of 475 patients and 354 FCGs were included in this analysis. Both patients and FCGs were primarily female, married, white, and had least a college education.

Table 1. Patient and FCG sociodemographic characteristics

Variable	Patients		p-Value	Family caregivers		p-Value
	Usual Care N (%)	Intervention N (%)		Usual Care N (%)	Intervention N (%)	
Gender						
Male	90 (41.1%)	99 (36.4%)	.305	59 (36.2%)	80 (39.4%)	.588
Female	129 (58.9%)	173 (63.6%)		104 (63.8%)	123 (60.6%)	
Education completed						
Elementary school	3 (1.4%)	2 (0.7%)	.716	2 (1.2%)	1 (0.5%)	.071
Secondary/high school	78 (35.8%)	93 (34.2%)		61 (37.4%)	55 (27.1%)	
College	137 (62.8%)	177 (65.1%)		100 (61.3%)	147 (72.4%)	
Marital status						
Single	17 (7.8%)	15 (5.5%)	.209	16 (9.9%)	31 (15.3%)	.308
Separated, divorced, widowed	55 (25.1%)	86 (31.7%)		13 (8.0%)	16 (7.9%)	
Married, partnered	147 (67.1%)	170 (62.7%)		133 (82.1%)	156 (76.8%)	
Live alone						
Yes	40 (18.3%)	56 (20.6%)	.568	6 (3.7%)	15 (7.4%)	.175
Employed						
>32 h per week	173 (79.0%)	235 (86.4%)	.039	56 (34.4%)	48 (23.6%)	.027
Ethnicity						
Hispanic/Latino	15 (6.8%)	19 (7.0%)	1.00	11 (6.7%)	24 (11.8%)	.015
Not Hispanic/Latino	204 (93.2%)	253 (93.0%)		145 (89.0%)	178 (87.7%)	
Unknown/unreported	0 (0%)	0 (0%)		7 (4.3%)	1 (0.5%)	
Race						
American Indian	2 (0.9%)	0 (0%)	.420	2 (1.2%)	0 (0%)	.001
Asian	32 (14.6%)	32 (11.8%)		25 (15.3%)	16 (7.9%)	
Black or African American	13 (5.9%)	14 (5.1%)		7 (4.3%)	5 (2.5%)	
Native Hawaiian or Other Pacific Islander	3 (1.4%)	7 (2.6%)		1 (0.6%)	10 (4.9%)	
White (includes Latino)	166 (75.8%)	217 (79.8%)		115 (70.6%)	167 (82.3%)	
Other/multiple	3 (1.4%)	2 (0.7%)		13 (8.0%)	5 (2.5%)	
Religion						
Protestant	90 (41.1%)	109 (40.1%)	.128	68 (42.0%)	81 (40.1%)	.075
Catholic	50 (22.8%)	76 (27.9%)		47 (29.0%)	56 (27.7%)	
Jewish	9 (4.1%)	14 (5.1%)		5 (3.1%)	16 (7.9%)	
Muslim	1 (0.5%)	1 (0.4%)		1 (0.6%)	0 (0%)	
Buddhist	7 (3.2%)	2 (0.7%)		7 (4.3%)	1 (0.5%)	
Mormon/LDS	2 (0.9%)	5 (1.8%)		2 (1.2%)	2 (1.0%)	
Jehovah's Witness	1 (0.5%)	2 (0.7%)		1 (0.6%)	1 (0.5%)	
Seventh Day Adventist	0 (0%)	2 (0.7%)		1 (0.6%)	1 (0.5%)	
Religion none	54 (24.7%)	47 (17.3%)		28 (17.3%)	33 (16.3%)	
Religion other	5 (2.3%)	14 (5.1%)		2 (1.2%)	11 (5.4%)	
Income						
≤\$50K	81 (37.0%)	93 (34.3%)	.382	39 (23.9%)	39 (19.2%)	.543
>\$50K	96 (43.8%)	135 (49.8%)		92 (56.4%)	123 (60.6%)	
Declined to state	42 (19.2%)	43 (15.9%)		32 (19.6%)	41 (20.2%)	
Age mean (SD)	63.52 (10.96)	66.17 (11.32)	.009	57.23 (13.16)	57.54 (14.31)	.834

The majority of patients and FCGs reported being affiliated with a religion, and these were primarily Protestant or Catholic. Approximately 101 (20.6%) of patients and 62 (16.8%) of FCGs reported no affiliation with a religious organization. Table 1 provides detailed sociodemographic characteristics for patients and FCGs included in this analysis.

Spiritual well-being scores at baseline and 12 weeks

Table 2 presents subscale, total, and item scores for patient and FCG spiritual well-being from baseline to 12 weeks. The FACIT-Sp-12 scores for patient spiritual well-being remained relatively stable from baseline

Table 2. Spiritual well-being scores for patients and family caregivers from baseline to 12 weeks

Patients (FACIT-Sp-12) Higher score = better spiritual well-being	Baseline		12 weeks	
	\bar{x}	SD	\bar{x}	SD
Meaning/Peace (range = 0–32)	25.79	5.56	26.27	5.86
Faith (range = 0–16)	10.93	4.93	11.04	5.16
Total (range = 0–48)	36.73	8.57	37.3	9.20
Items (range = 0–4)				
I feel peaceful.	2.78	1.14	2.93	1.11
I have a reason for living.	3.73	.66	3.69	.73
My life has been productive.	3.50	.82	3.57	.78
I feel peace of mind.	3.03	1.10	3.18	1.02
I feel a sense of purpose in my life.	3.37	.98	3.38	.99
I am able to reach down deep into myself for comfort.	3.01	1.08	3.09	1.08
I feel a sense of harmony within myself.	2.83	1.15	2.99	1.09
My life has meaning and purpose.	3.55	.88	3.61	.79
I find comfort in my faith or spiritual beliefs.	2.79	1.47	2.80	1.52
I find strength in my faith or spiritual beliefs.	2.77	1.49	2.77	1.54
My illness has strengthened my faith or spiritual beliefs.	2.39	1.62	2.36	1.68
I know that whatever happens with my illness, things will be okay.	3.01	1.26	3.11	1.22
Family Caregivers (COH-QOL-FCG) Range = 0–10; higher score = better spiritual well-being				
Subscale score	6.38	1.84	6.42	1.68
Items				
Is the amount of support you receive from religious activities sufficient to meet your needs?	5.82	3.86	6.07	3.74
Is the amount of support you receive from personal spiritual activities such as prayer or meditation sufficient to meet your needs?	6.83	3.25	7.12	3.16
How much uncertainty do you feel about your family member's future?	3.80	3.08	4.02	2.85
Has your family member's illness made positive changes in your life?	4.49	3.36	4.85	3.21
Do you have a purpose/mission for your life or a reason for being alive?	8.31	2.17	8.44	1.94
How hopeful do you feel today?	7.62	2.20	7.41	2.09
Rate your overall spiritual well-being?	7.78	2.22	7.57	2.37

to 12 weeks, with trends for improvement seen for all subscales and items. Individual items that scored below a 3 (range=0–4; higher score=better spiritual well-being) in the FACIT-Sp-12 included items on feeling peace and harmony, finding comfort and strength in faith or spiritual beliefs, and the illness having strengthened faith or spiritual beliefs. For FCGs, the overall spiritual well-being subscale score on the COH-QOL-FCG was moderate. Specific items that scored below a 5 (range=0–10; higher score=better spiritual well-being) included uncertainty about the family member's future and family member's illness resulting in positive changes in the FCG's life.

Spiritual well-being outcomes by religious affiliations

Multivariate analysis of spiritual well-being outcomes revealed that patients who reported having a religious affiliation had significantly better scores for the Faith subscale of the FACIT-Sp-12 compared to patients who reported no religious affiliations at 12 weeks (Table 3). For specific FACIT-Sp-12 items, non-affiliated patients had significantly better scores for feeling a sense of harmony within oneself (3.2 versus 2.9; $p = .043$). Religiously affiliated patients reported significantly better scores in finding strength and comfort in faith or spiritual beliefs ($p < .001$) and illness having strengthened faith and spiritual beliefs (2.5 versus 2.1; $p = .012$). There were no statistically significant differences in spiritual well-being outcomes by religious affiliation for FCGs (Table 4).

Spiritual well-being outcomes by group

Multivariate analysis of spiritual well-being outcomes by group revealed that patients who received interdisciplinary palliative care had significantly better scores for the Meaning/Peace subscale of the FACIT-Sp-12 compared to patients who received usual care (Table 3). Significant differences were also observed in favor of the intervention group for FACIT-Sp-12 items for feeling peace of mind, able to reach deep down for comfort, and sense of harmony within oneself ($p < .001$ for all items). For spiritual well-being, FCGs in the usual care group had significantly better scores for overall spiritual well-being compared to FCGs in the intervention group ($p = .049$).

Discussion

Spiritual well-being is a core component of quality cancer care, with mounting evidence pointing to its importance for patients and FCGs coping with a cancer diagnosis [10]. It is associated with better QOL, psychosocial functioning, and less aggressive medical interventions at the

Table 3. Multivariate analysis of spiritual well-being outcomes at 12 months by religious affiliation and group for patients

Outcome	By religious affiliation				p-Value	By group				p-Value
	Yes (N = 376)		No (N = 99)			Usual care (N = 219)		Intervention (N = 272)		
	$\bar{x} \pm SD$	\bar{x}^a	$\bar{x} \pm SD$	\bar{x}^a		$\bar{x} \pm SD$	\bar{x}^a	$\bar{x} \pm SD$	\bar{x}^a	
Patients <i>Higher score = better spiritual well-being</i>										
Meaning/Peace (range = 0–32)	26.43 ± 5.80	26.2	25.67 ± 6.07	26.5	.555	24.75 ± 6.04	25.3	27.48 ± 5.42	27.0	<.001
Faith (range = 0–16)	12.12 ± 4.55	11.3	6.93 ± 5.30	10.2	.010	10.61 ± 4.98	11.0	11.39 ± 5.28	11.1	.769
I have a reason for living.	3.74 ± .66	3.7	3.48 ± .93	3.6	.232	3.60 ± .78	3.7	3.76 ± .68	3.7	.989
My life has been productive.	3.59 ± .74	3.6	3.47 ± .93	3.5	.806	3.40 ± .86	3.5	3.71 ± .69	3.6	.086
I feel peace of mind.	3.20 ± 1.01	3.2	3.04 ± 1.11	3.1	.572	2.92 ± 1.08	3.0	3.38 ± .93	3.3	<.001
I feel a sense of purpose in my life.	3.43 ± .94	3.4	3.21 ± 1.18	3.4	.600	3.28 ± 1.04	3.4	3.47 ± .94	3.4	.768
I am able to reach down deep into myself for comfort.	3.08 ± 1.09	3.0	3.07 ± 1.14	3.2	.088	2.71 ± 1.16	2.8	3.40 ± .92	3.3	<.001
I feel a sense of harmony within myself.	2.98 ± 1.09	2.9	2.95 ± 1.15	3.2	.043	2.65 ± 1.14	2.8	3.26 ± .97	3.2	<.001
My life has meaning and purpose.	3.68 ± .68	3.6	3.35 ± 1.07	3.6	.452	3.47 ± .93	3.6	3.74 ± .62	3.7	.089
I find comfort in my faith or spiritual beliefs.	3.20 ± 1.24	2.9	1.46 ± 1.64	2.4	<.001	2.66 ± 1.52	2.8	2.97 ± 1.49	2.8	.924
I find strength in my faith or spiritual beliefs.	3.17 ± 1.26	2.9	1.38 ± 1.62	2.4	<.001	2.60 ± 1.55	2.8	2.96 ± 1.50	2.8	.589
My illness has strengthened my faith or spiritual beliefs.	2.72 ± 1.55	2.5	1.12 ± 1.51	2.1	.012	2.15 ± 1.65	2.3	2.58 ± 1.67	2.4	.488
I know that whatever happens with my illness, things will be okay.	3.20 ± 1.15	3.1	2.81 ± 1.43	3.2	.548	3.21 ± 1.15	3.3	3.04 ± 1.28	3.0	.014

^aAdjusted means.

Table 4. Multivariate analysis of spiritual well-being outcomes at 12 months by religious affiliation and group for family caregivers

Outcome	By religious affiliation				p-Value	By group				p-Value
	Yes (N = 292)		No (N = 62)			Usual care (N = 157)		Intervention (N = 197)		
	$\bar{x} \pm SD$	\bar{x}^a	$\bar{x} \pm SD$	\bar{x}^a		$\bar{x} \pm SD$	\bar{x}^a	$\bar{x} \pm SD$	\bar{x}^a	
Family caregivers <i>Range = 0–10; higher score = better spiritual well-being</i>										
Total score	6.65 ± 1.57	6.5	5.40 ± 1.76	6.3	.269	6.53 ± 1.80	6.5	6.32 ± 1.59	6.3	.049
Is the amount of support you receive from religious activities such as going to church or temple sufficient to meet your needs?	6.49 ± 3.49	6.1	3.86 ± 4.31	5.9	.674	6.48 ± 3.58	6.3	5.72 ± 3.84	5.9	.229
Is the amount of support you receive from personal spiritual activities such as prayer or meditation sufficient to meet your needs?	7.50 ± 2.85	7.2	5.08 ± 4.14	7.0	.606	7.20 ± 3.14	7.1	7.05 ± 3.25	7.1	.881
How much uncertainty do you feel about your family member's future?	4.19 ± 2.91	4.1	3.50 ± 2.48	3.8	.498	4.20 ± 2.91	4.2	3.96 ± 2.80	3.9	.269
Do you have a purpose/mission for your life or a reason for being alive?	8.55 ± 1.83	8.5	8.14 ± 2.21	8.5	.950	8.43 ± 2.12	8.4	8.47 ± 1.75	8.5	.854
How hopeful do you feel today?	7.56 ± 1.95	7.5	6.81 ± 2.48	7.2	.421	7.50 ± 2.04	7.5	7.34 ± 2.14	7.3	.295

^aAdjusted means.

end of life [10,15,17,20,34]. In this analysis, we aimed to examine the spiritual well-being outcomes for lung cancer patients and FCGs enrolled in a prospective trial that tested the effect of an interdisciplinary palliative care intervention on QOL-related outcomes. Recently, several psychotherapeutic interventions were tested in palliative care settings to improve psychological well-being in cancer patients. These include dignity therapy [35] and meaning-centered psychotherapy (MCP), and MCP was successful in improving psychological and spiritual distress in advanced cancer patients [36]. We focused on

spiritual outcomes at the subscale and item-specific level based on patient and FCG reported religious affiliations. Examining differences at the item-specific level may allow for better deconstruction of the multidimensionality of spiritual well-being.

Our findings by religious affiliation revealed that patients who reported no religious affiliations had better outcomes in relation to sense of harmony within oneself. The FACIT-Sp-12, our selected spiritual well-being measure, includes items that are focused on life's meaning, coherence, and purpose (Meaning/Peace subscale). This

suggests that religious affiliation may not be associated with an individual's ability to derive spiritual benefits such as coherence and sense of harmony in life. Conversely, patients in our study who are religiously affiliated reported better outcomes in three items within the Faith subscale that are focused on finding strength and comfort in religious and spiritual beliefs. This finding provides further empirical support of the multidimensionality of spiritual well-being and the validity of the distinct two-factor construct of the FACIT-Sp-12. The current evidence on religion/spiritual well-being suggests that religion may be more likely a means of coping or finding comfort, and religion's primary benefit may be to facilitate the creation of meaning, purpose, and coherence in life [37]. However, spiritual distress may occur in situations where religious beliefs and practices fail to provide meaning or provide negative meaning, such as feeling abandoned by God [10,37]. More recent investigations of spiritual well-being using the FACIT-Sp-12 suggest that a three-factor construct of meaning, peace, and faith may allow for further examination of the different spiritual dimensions that contribute to improved QOL and coping [38].

We also aimed to examine spiritual well-being outcomes by group (usual care versus intervention). Our interdisciplinary palliative care intervention resulted in statistically significant improvements in the Meaning/Peace subscale and 4 specific items within the FACIT-Sp-12. These significant items were all included as topics in the spiritual well-being educational session of the intervention, and suggest that the teaching content was effective in addressing the patient's spiritual needs in relation to peace of mind, sense of harmony, and finding strength and comfort. We were unable to determine whether the improvements in spiritual well-being scores are clinically meaningful differences, as the data is available only by ECOG performance status ratings [32]. A recent article described reference values of the measure in a large sample of adult cancer survivors, but lung cancer patients were not included in the sample [39].

We did not observe a significant difference in spiritual well-being outcomes based on religious affiliation in FCGs. Our measure of spiritual well-being in FCGs (Spiritual Well-Being subscale of the COH-QOL-FCG) may not have the sensitivity to capture differences based on religious/spiritual well-being. We also observed that FCGs in the usual care group reported significantly improved spiritual well-being compared to the intervention

group. This finding may be explained by an insufficiency in the intervention 'dose' and insufficient content on supporting FCG's spiritual well-being.

This study and analysis has several limitations. First, the analysis presented is primarily secondary from data obtained in the setting of a prospective, quasi-experimental trial of interdisciplinary palliative care in lung cancer patients and FCGs. The design and analysis approach may result in bias in comparison of findings by religious affiliations and by group. Second, we selected different measures of spiritual well-being for patients and FCGs; therefore a direct comparison of potential similarities and differences in the trajectory of patient and FCG spiritual well-being was not possible. Finally, this was a single site trial, where existing spiritual care resources within our institution may be different than other settings. Therefore, findings may not be generalizable to other settings. Research is needed to further define the construct and dimensions of spirituality/religion, assess the reliability and validity of spiritual well-being measures in more diverse populations and religions, and describe spiritual well-being outcomes that are clinically meaningful in cancer care.

In conclusion, this study provides support for the importance of spiritual well-being in oncology and as a core component of palliative care and overall QOL. Our findings support the multidimensionality of spiritual well-being that includes constructs such as meaning and faith, and the potential impact on QOL for lung cancer patients and FCGs with or without religious affiliations. Finally, our results support the inclusion of spiritual well-being content in palliative care interventions that target the spiritual needs of patients and FCGs.

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Conflict of interest

The authors have declared no conflicts of interest.

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