

Caregiving experiences predict changes in spiritual well-being among family caregivers of cancer patients

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Abstract

Objective: Although enhanced spiritual well-being has been linked to positive mental health outcomes among family caregivers of cancer patients, little is known regarding predictors of spiritual well-being in this population. The current study aimed to examine caregiving experiences as predictors of change in family caregivers' spiritual well-being during the initial months following the patient's cancer diagnosis.

Methods: Seventy family caregivers of newly diagnosed cancer patients (74% female, mean age = 59 years) participated in this longitudinal survey. Caregivers completed baseline questionnaires shortly before staying with the patient at an American Cancer Society Hope Lodge. Baseline questionnaires assessed caregiving experiences (i.e., self-esteem related to caregiving, family support for providing care, impact of caregiving on finances, and impact of caregiving on one's schedule). In addition, caregivers' spiritual well-being (i.e., meaning in life, peace, and faith) was assessed at baseline and 4-month follow-up.

Results: In univariate analyses, all caregiving experiences studied were associated with one or more aspects of spiritual well-being at 4-month follow-up. However, in the multivariate analysis, the only caregiving experience associated with aspects of spiritual well-being at 4-month follow-up was caregivers' perceptions of family support. Specifically, lack of family support was associated with lower levels of meaning and peace.

Conclusions: Findings point to the importance of family support in facilitating the search for meaning and peace shortly after a loved one's cancer diagnosis and suggest that interventions targeting caregivers' support system may enhance their spiritual well-being.

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Background

Cancer is a stressful experience not only for patients but also for their family caregivers who assist with self-care or medical tasks and provide informational, emotional, or financial support [1]. Caregiving demands affect family caregivers' mental health [2,3] with 20% to 66% reporting significant anxiety or depressive symptoms [3–5]. Furthermore, as cancer often poses a threat to life, family caregivers are likely to experience existential concerns that may impact their spiritual well-being (SWB) [6].

Spiritual well-being of family caregivers

When faced with a life-threatening stressor such as cancer, many individuals engage in meaning-making or adjustment of their worldview to accommodate the stressor [6,7]. According to theories of meaning-making, emotional and cognitive processing of the stressful experience facilitates the construction of meaning [7], which in turn has been related to enhanced quality of life [8,9].

Spiritual well-being, including a sense of meaning in life, peace, and comfort in faith, has been conceptualized as a domain of quality of life for cancer patients and older adults [10,11]. In general, cancer patients have reported mean global SWB scores at the upper end of the scale, with a wide range of SWB scores represented across studies [12–14]. Cancer caregivers' SWB has received less research attention, with a few studies indicating that their levels of SWB are comparable with those of cancer patients and relatively stable over time [15–19].

Preliminary evidence suggests that poorer overall SWB (i.e., combined score for meaning/peace and faith) is associated with worse mental health among cancer caregivers [16,18,20–22]. Only one study has examined relationships between specific aspects of SWB (i.e., meaning, peace, or faith) and mental health among cancer caregivers and found that, whereas overall SWB and feelings of peace were related to mental health, the meaning and faith aspects of SWB were not [16].

Although the cancer caregiving literature on SWB is limited [16,18,20–22], a number of studies have examined relationships between specific aspects of SWB and mental

health in cancer patients [23]. These studies have found that higher levels of meaning and peace are consistently related to better mental health outcomes [13,16,24,25]. The relationship between faith and mental health has been less consistent, with only some studies reporting significant relationships [13,16,24,25]. Taken together, research with cancer patients and caregivers suggests that SWB is positively associated with mental health.

Caregiving experiences and spiritual well-being

Grounded in Lazarus and Folkman's [26] cognitive stress theory, Nijboer and colleagues [1] proposed a conceptual framework of the caregiving process in which perceptions of the situation (e.g., belief that sufficient social resources are available to meet care demands) impact the well-being of caregivers. In support of this conceptual framework, a number of subjective caregiving experiences have been consistently related to poorer mental health in cancer caregivers including greater interference of caregiving with one's schedule and lifestyle [2,27–29], poorer social functioning and perceptions of less familial and community support [2,30], greater caregiving stress and burden [20,31,32], less self-esteem related to caregiving [33], and greater impact of caregiving on finances [34,35]. However, the impact of caregiving experiences on cancer caregivers' SWB has received limited research attention. Preliminary evidence suggests that greater caregiving stress and lower levels of self-esteem related to caregiving are correlated with worse overall SWB among cancer caregivers [36]. In contrast, another study found that the quantity of care provided (e.g., hours spent providing care and frequency of providing different types of care) was not significantly related to overall SWB among cancer caregivers [15]. Perceptions of greater social support, however, have been correlated with better overall SWB among cancer caregivers [21]. Theory suggests that low levels of social support may negatively impact caregivers' SWB, as caregivers have fewer opportunities to engage in meaning-making with important others [7].

The present study extends prior cross-sectional work on cancer caregiving experiences and global SWB [15,36] by examining associations between cancer caregiving experiences and changes in specific aspects of cancer caregivers' SWB over time. Furthermore, whereas prior studies on relations between cancer caregiving experiences and SWB have exclusively focused on the long-term survivorship period [15,36], this research examined caregivers of patients during the initial months following the cancer diagnosis, a period during which existential concerns may be heightened [37]. Caregivers were assessed shortly before their stay at an American Cancer Society (ACS) Hope Lodge and 4 months later, a point at which the majority of study participants had returned to their residence.

Study hypotheses were based on theories of meaning-making and the caregiving process [1,6,7] and prior findings linking subjective caregiving experiences to caregivers' mental health outcomes [1,2,38] and overall SWB [36]. We hypothesized that higher self-esteem from caregiving shortly after the patient's cancer diagnosis would be associated with increases in caregivers' SWB (i.e., meaning in life, peace, and faith) at 4-month follow-up. We also predicted that caregivers' perceptions of lack of family support for providing care shortly after the cancer diagnosis would be associated with decreases in their SWB at follow-up. Finally, we hypothesized that greater negative impact of caregiving on caregivers' schedules and finances soon after the cancer diagnosis would be related to decreases in their SWB at follow-up.

Methods

Participants and procedure

All study procedures were approved by the Emory University Institutional Review Board. This ACS Hope Lodge study was designed to examine the effect of social factors on quality of life among recently diagnosed cancer patients and their family caregivers entering the Hope Lodge in Rochester, Minnesota. ACS's Hope Lodge houses patients and their family caregivers at no cost if the patient is undergoing outpatient cancer treatment at least three times weekly and resides greater than 40 miles away from the cancer treatment facility. Patients and unpaid family caregivers were recruited at least 2 days prior to their scheduled move into the Hope Lodge. To be eligible for this study, patients and caregivers had to be 18 years of age or older and able to speak and read English.

Informed consent was obtained face-to-face at locations convenient for prospective participants (e.g., clinic appointments and hotel rooms) before their stay at the Hope Lodge. A total of 154 patients and 143 caregivers were approached, as 11 patients were not accompanied by a family member. Nearly all (141/143) caregivers were eligible, and 106 agreed to participate in the study (a 75% response rate). Common reasons for caregivers' study refusal included feeling too overwhelmed with responsibilities and the time commitment.

Participants completed questionnaires at the time of enrollment (typically within a week before arriving at the Hope Lodge) and 4 months later by postal mail. Phone calls were made to participants to remind them to complete the questionnaires. Participants did not receive compensation for completing the baseline survey but received \$15 for participating in the 4-month follow-up survey.

Attrition occurred over the 4-month study period such that 15% of 106 consenting caregivers were lost to follow-up, 4% were no longer eligible owing to patient

death, and 3% declined to continue study participation. Of the 83 participating caregivers, 70 provided complete data on all study variables at both baseline and 4-month follow-up and were included in the current analyses. Caregivers who were withdrawn from the study or provided incomplete data ($n=36$) did not differ from those with complete data ($n=70$) with respect to baseline demographics and study variables ($ps > 0.05$).

Measures

Demographic and medical characteristics

Demographic and medical information was collected via self-report questionnaires. Caregivers reported their age, gender, ethnicity, education level, income, employment status, marital status, and relationship to the patient. Patients reported their date of diagnosis, cancer treatment, and cancer type and stage.

Characteristics of the caregiving experience

Caregivers' perceptions of the caregiving experience were measured with four subscales of the caregiver reaction assessment [39]. The five-item impact on schedule and three-item impact on finances subscales assess the extent to which providing care affects personal activities and family finances, respectively. The seven-item caregiver's esteem subscale assesses the extent to which caregiving enhances self-esteem. Finally, the five-item lack of family support subscale measures caregivers' perceptions of family support for providing care. Items for the four subscales are rated on a 5-point scale from 1 (*strongly disagree*) to 5 (*strongly agree*). Composite scores were calculated by averaging relevant items (after reverse coding, as necessary), with higher scores indicating greater impact on schedule, greater impact on finances, higher self-esteem related to caregiving, and greater perceived lack of family support. The caregiver reaction assessment has demonstrated construct validity [39] and acceptable internal consistency reliability in research on caregivers of cancer patients [28]. In this study, internal consistency reliabilities for the subscales at baseline were good ($0.76 < \alpha < 0.88$).

Spiritual well-being

The meaning, peace, and faith subscales of the 12-item Functional Assessment of Chronic Illness Therapy—Spiritual Well-being Scale (FACIT-Sp) [13,40] were used to assess aspects of caregivers' SWB related to the patient's cancer diagnosis. Items referring to personal illness in the original FACIT-Sp were rephrased to refer to the patient's illness. Each item is rated on a 5-point scale from 0 (*not at all*) to 4 (*very much*). Three 4-item composite scores were calculated by averaging relevant items (after reverse coding, as necessary), with higher scores indicating a greater sense of meaning, peace, and

faith in the context of the patient's illness. The FACIT-Sp has shown good convergent validity and internal consistency reliability ($0.78 < \alpha < 0.88$) [13,40]. In this study, internal consistency reliabilities for the subscales were good at baseline ($0.80 < \alpha < 0.88$) and 4-month follow-up ($0.83 < \alpha < 0.89$).

Statistical methods

Data were analyzed with SPSS statistical software (version 20.0; SPSS, Chicago, IL, USA). Means and standard

Table 1. Sample characteristics

Characteristic	Mean or frequency
Caregiver baseline demographics (N = 70)	
Average age	59.0 years (range: 24–79, SD: 13.1)
Female	74.3%
Race	
Caucasian	95.7%
African-American	1.4%
Other	2.8%
Education	
High school or less	34.3%
Some college	30.0%
College degree or higher	35.7%
Annual household income	
<\$40,000	21.4%
\$40,000–\$74,999	40.0%
>\$75,000	21.4%
Prefer not to answer	17.1%
Married/marriage equivalent	100%
Employment status	
Employed	47.1%
Unemployed	51.4%
Relationship to the patient	
Spouse/partner	87.1%
Child	5.7%
Parent	2.9%
Other	4.2%
Patient medical characteristics (N = 70)	
Average time since diagnosis	0.24 months (range: 0–2.1, SD = 0.30)
Cancer type	
Digestive system	21.4%
Genital system	15.6%
Breast	11.7%
Brain and other nervous system	9.1%
Respiratory system	7.1%
Lymphoma	6.5%
Other	20.0%
Missing	9.7%
Cancer stage	
0	2.9%
I	15.7%
II	5.7%
III	24.3%
IV	5.7%
Unstaged	7.1%
Missing/unknown	38.6%

deviations for continuous variables and frequencies for categorical variables were calculated. Zero-order correlations between study variables also were computed. A multivariate general linear modeling analysis was used to examine the extent to which baseline caregiving characteristics (i.e., lack of family support, caregiver’s esteem, impact on schedule, and impact on finances) predicted changes in three aspects of SWB (i.e., meaning in life, peace, and faith) from baseline to 4-month follow-up. Caregiver age, gender, and education level were included as covariates in multivariate analyses, as these variables have been associated with SWB in cancer caregivers [36].

Results

Descriptive statistics

As shown in Table 1, caregivers were primarily female (74%), spouses/partners of the patient (87%), and Caucasian (96%) with a mean age of 59 years (*SD* = 13). The median household income was over \$40,000 with a broad range that represented the entire scale. Most caregivers had completed at least some college, and nearly half (47%) were employed. The average time since the patient’s cancer diagnosis at baseline was 0.24 months (*SD* = 0.30 months). Patients had diverse cancer types with the most common being cancers of the digestive system (21%), genital system (16%), and breast (12%). Most patients were receiving chemotherapy (58%) or radiation (94%) at the time of the baseline assessment.

Descriptive statistics for caregiving experiences and SWB are found in Table 2. Regarding the baseline

measure of caregiving experiences, the subscale means were comparable with those found in other studies of caregivers at various points across the cancer trajectory [28,41]. On average, caregivers in the current study disagreed with statements indicating a lack of family support for providing care and agreed with statements indicating high self-esteem derived from caregiving. Furthermore, on average, caregivers neither agreed nor disagreed with statements indicating an impact of caregiving on their schedule and family finances. Regarding average levels of SWB at baseline and follow-up, caregivers reported experiencing ‘quite a bit’ of meaning in life and reliance on faith and endorsed feeling ‘somewhat’ peaceful in the context of caregiving.

Zero-order correlations

Zero-order correlations among study variables are presented in Table 2. All caregiving experiences were significantly correlated with each other at baseline, and all aspects of SWB (i.e., meaning, peace, and faith) were positively correlated with each other at each time point and across time points. Furthermore, baseline caregiving experiences were correlated with aspects of SWB at 4-month follow-up. Specifically, lack of family support for caregiving was related to lower levels of meaning, peace, and faith. In addition, greater self-esteem from caregiving was correlated with higher levels of peace, but not meaning and faith. Finally, greater impact of caregiving on one’s schedule was related to lower levels of meaning and peace, whereas greater impact of caregiving on finances was only related to lower levels of meaning.

Table 2. Pearson’s correlations, means, and standard deviations for study variables

Study variable	1	2	3	4	5	6	7	8	9	10	11	12	13
Baseline													
1. Age													
2. Gender ^a	-0.14												
3. Education ^b	0.04	0.10											
4. Meaning	-0.04	0.21	0.24*										
5. Peace	0.20	0.10	0.11	0.70**									
6. Faith	0.10	0.18	-0.04	0.35**	0.50**								
7. Lack of family support	-0.31**	-0.02	-0.29*	-0.44**	-0.51**	-0.32**							
8. Self-esteem from caregiving	0.12	-0.06	-0.02	0.43**	0.30*	0.26*	-0.29*						
9. Impact of caregiving on schedule	-0.26*	0.05	-0.16	-0.30*	-0.50**	-0.14	0.50**	-0.26*					
10. Impact of caregiving on finances	-0.02	-0.31**	-0.30*	-0.30*	-0.23	-0.14	0.50**	-0.28*	0.36**				
4-month follow-up													
11. Meaning	0.09	0.20	0.10	0.49**	0.48**	0.33**	-0.66**	0.17	-0.35**	-0.25*			
12. Peace	-0.02	-0.01	0.12	0.55**	0.67**	0.47**	-0.54**	0.25**	-0.40**	-0.20	0.79**		
13. Faith	0.20	0.13	-0.00	0.35**	0.45**	0.84**	-0.31**	0.22	-0.13	-0.14	0.44**	0.53**	
Mean				12.71	8.93	11.39	1.68	4.37	2.79	2.84	12.89	10.17	11.19
Standard deviation				3.08	3.95	4.41	0.67	0.53	1.04	1.03	3.13	3.60	4.45

N = 70. Possible range for lack of family support, self-esteem from caregiving, impact of caregiving on schedule, and impact of caregiving on finances = 1–5. Possible range for meaning, peace, and faith = 0–16.

^aCoded (female = -1, male = +1).

^bCoded (less than college degree = -1, college degree or higher = +1).

**p* < 0.05.

***p* < 0.01.

Table 3. Hierarchical general linear model predicting domains of spiritual well-being at the 4-month follow-up

	Meaning				Peace				Faith			
	B	t	95% CI	p	B	t	95% CI	p	B	t	95% CI	p
Block 1: baseline demographics and spiritual well-being	$R^2 = 0.357$				$R^2 = 0.484$				$R^2 = 0.710$			
Age	0.00	0.01	-0.05, 0.05	0.99	0.01	0.53	-0.04, 0.07	0.60	0.00	0.06	-0.05, 0.05	0.95
Gender ^a	0.77	0.98	-0.80, 2.33	0.33	0.78	0.97	-0.83, 2.40	0.34	0.22	0.29	-1.28, 1.71	0.78
Education ^b	-0.72	-1.06	-2.09, 0.64	0.30	-0.42	-0.59	-1.82, 0.99	0.56	-0.07	-0.11	-1.38, 1.23	0.91
Meaning	0.21	1.32	-0.11, 0.52	0.19	0.03	0.18	-0.29, 0.35	0.86	0.02	0.15	-0.28, 0.32	0.89
Peace	0.26	2.02	0.00, 0.52	0.05	0.52	3.93	0.26, 0.79	0.001	0.05	0.42	-0.20, 0.30	0.68
Faith	0.11	1.28	-0.06, 0.28	0.21	0.13	1.45	-0.05, 0.30	0.15	0.82	10.08	0.66, 0.98	0.001
Block 2: baseline caregiving experiences	$\Delta R^2 = 0.180$				$\Delta R^2 = 0.045$				$\Delta R^2 = 0.001$			
Lack of family support	-2.70	-4.49	-3.91, -1.50	0.001	-1.48	-2.12	-2.88, -0.08	0.04	-0.13	-0.20	-1.49, 1.22	0.85
Self-esteem from caregiving	-0.56	-0.87	-1.83, 0.72	0.39	0.14	0.19	-1.34, 1.62	0.85	-0.04	-0.06	-1.47, 1.39	0.95
Impact on schedule	-0.01	-0.03	-0.73, 0.71	0.97	-0.15	-0.37	-0.99, 0.68	0.71	0.19	0.47	-0.62, 1.00	0.64
Impact on finances	0.26	0.69	-0.48, 0.99	0.49	0.23	0.54	-0.62, 1.09	0.59	-0.14	-0.34	-0.97, 0.69	0.74

N = 70.

^aCoded (female = -1, male = +1).

^bCoded (less than college degree = -1, college degree or higher = +1).

Multivariate analysis of caregiving experiences as predictors of spiritual well-being

Table 3 displays results from the multivariate general linear modeling analysis of caregiving experiences as predictors of change in caregivers' SWB, controlling for caregiver age, gender, and education. Most control variables (i.e., age, gender, education level, and baseline meaning) were not significantly related to meaning, peace, or faith at 4-month follow-up. However, baseline levels of peace and faith were correlated with these respective outcomes over time. Together, the covariates and baseline meaning, peace, and faith in the first block of the model accounted for 36% of the variance in meaning, 48% of the variance in peace, and 71% of the variance in faith at 4-month follow-up. Regarding the main study findings, the four types of caregiving experiences accounted for an additional 18% of the variance in meaning, 5% of the variance in peace, and 0.001% of the variance in faith, above and beyond demographic covariates and baseline meaning, peace, and faith. When examining specific aspects of caregiving in the model, lack of family support for caregiving was significantly related to lower levels of meaning and peace, but not faith, at 4-month follow-up. Self-esteem from caregiving and the impact of caregiving on one's schedule and finances, all of which showed significant univariate correlations with aspects of SWB at follow-up, were not significantly correlated with any aspects of SWB in the multivariate analysis.

Conclusions

The present study examined the extent to which caregiving experiences were related to changes in aspects of

caregivers' SWB during the initial months following a family member's cancer diagnosis. As predicted, a perceived lack of family support for caregiving was associated with decreases in caregivers' sense of meaning in life and peace over the 4-month study period. This finding is consistent with theory suggesting that low levels of social support hinder meaning-making, as individuals have few opportunities to process the stressful experience [7]. Caregivers often process existential concerns by talking about their concerns with important others [42]; thus, caregivers' meaning-making may be hindered when they feel that others are unavailable or unreceptive to discussions of their concerns [7]. In addition, this finding converges with prior research [28,38] and theory [1] linking perceptions of reduced social support and caregiving assistance from family members to poorer psychological well-being among cancer caregivers. Our result extends this research by providing initial evidence that family support is critical to caregivers' sense of SWB during the months following a family member's cancer diagnosis.

Caregivers' perceptions of the impact of caregiving on their schedule, finances, and self-esteem at baseline were correlated at the univariate level with aspects of SWB at 4-month follow-up but did not predict change in SWB over the 4-month study period. Regarding univariate correlations, mixed findings were obtained. For example, greater self-esteem related to caregiving was associated with higher levels of peace, but not meaning or faith. One potential explanation for the null findings is that statistical power was insufficient for detecting small effect sizes. Null multivariate findings might also be attributable to high correlations between aspects of SWB at baseline and 4 months later.

None of the caregiving experiences examined in this study were associated with changes in caregivers' faith.

In contrast to the meaning and peace subscales of the FACIT-Sp, the faith subscale has been correlated with measures of religiosity, which is thought to be a stable trait in adulthood [13,43]. In the present study, little change in caregivers' faith occurred across the 4-month study period. To our knowledge, this study is the first to specifically examine potential changes in caregivers' faith during the initial months following a loved one's cancer diagnosis, whereas prior research has documented the stability of caregivers' global SWB across the cancer trajectory [18,19]. Although a cancer diagnosis may result in heightened existential concerns [6], the present findings suggest that caregivers' comfort from religious beliefs is relatively stable during this adjustment period.

Limitations of this study should be noted. The sample primarily consisted of Caucasian, middle-class women. Future studies should include caregivers with greater socioeconomic, gender, and ethnic diversity. Another limitation is the attrition over the 4-month study period. Caregivers who completed all time points may have differed on unmeasured characteristics from caregivers who did not complete all of the time points, which may have influenced the findings. Furthermore, all variables in this study, including patient medical characteristics, were self-reported, which resulted in extensive missing data with regard to disease stage. Missing data and small disease subgroups reduced statistical power such that medical characteristics were not examined as predictors of caregivers' SWB. Future research should include medical record data and objective measures of caregiving experiences and well-being. Finally, caregivers staying at the Hope Lodge might have differed from the general population of cancer caregivers, as they all traveled at least 40 miles from their residence to a cancer treatment center in Rochester, MN. Future research should examine whether relationships between caregiving experiences and aspects of SWB differ for caregivers who reside in their typical social environment. In addition, documenting the

number of family members providing care to the patient may provide an indication of the caregivers' support system.

This study has important research and clinical implications. Results suggest that perceptions of the caregiving experience, especially perceptions of familial support, are related to caregivers' sense of meaning and peace during the initial period of adjustment to the cancer diagnosis. These findings underscore the role of the family in facilitating meaning-making following a loved one's cancer diagnosis and suggest that interventions targeting caregivers' support system may enhance their SWB. For example, clinicians could teach caregivers strategies for enhancing the quality of their support network (e.g., asking for help and communicating feelings). In addition, meaning-centered group psychotherapy, which involves the receipt of support from other group members and the discussion of meaning within a cancer context, has shown promise for enhancing advanced cancer patients' SWB [44,45] and may be extended to cancer caregivers or patient-caregiver dyads in future studies. A family-centered approach to cancer care may not only reduce patient and caregiver distress but may also enhance their spiritual resources for coping with the illness.

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Conflict of interest

The authors indicated no potential conflicts of interest.

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