

# Spirituality moderates the relationship between cancer caregiver burden and depression

## Original Article


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### Abstract

**Objectives.** Cancer has become a chronic disease that requires a considerable amount of informal caregiving, often quite burdensome to family caregivers. However, the influence of spirituality on the caregivers' burden and mental health outcomes has been understudied. This study was to examine how caregiver burden, spirituality, and depression change during cancer treatment and investigate the moderating role of spirituality in the relationship between caregiver burden and depression for a sample of caregivers of persons with cancer.

**Methods.** This secondary analysis used a longitudinal design employing 3 waves of data collection (at baseline, 3 months, and 6 months). Family caregivers completed the Caregiver Reaction Assessment, Spiritual Perspective Scale, and the PROMIS® depression measure. Linear mixed model analyses were used, controlling for pertinent covariates.

**Results.** Spirituality, total caregiver burden, and depression remained stable over 6 months. More than 30% of the caregivers had mild to severe depressive symptoms at 3 time points. There was evidence of overall burden influencing depression. Of note was a protective effect of caregivers' spirituality on the relationship between depression and caregiver burden over time ( $b = -1.35$ ,  $p = .015$ ). The lower the spirituality, the stronger the relationship between depression and burden, especially regarding subscales of schedule burden, financial burden, and lack of family support.

**Significance of results.** Spirituality was a significant resource for coping with caregiving challenges. This study suggests that comprehensive screening and spiritual care for cancer caregivers may improve their cancer caregiving experience and possibly influence the care recipients' health.

## Introduction

Along with advances in cancer treatment, the population of new cancer cases and survivors grows globally. In 2019, almost 17 million persons with a history of cancer were alive in the United States (American Cancer Society 2020). As an integral partner in cancer care, family caregivers provide varied care activities and support to individuals with cancer (National Alliance for Caregiving 2016). At the same time, family caregivers who contribute to care recipients' health are often considered as second-order patients (Sherman 2019). Cancer family caregivers are confronted with complex, stressful, and demanding caregiving situations across the cancer trajectory (Girgis et al. 2013). The multifaceted nature of the burden experienced from facing an array of physical, psychological, emotional, social, and financial stressors may impact the caregiver's health (Adelman et al. 2014). Informal caregiving is associated with significant mental health challenges (Alam et al. 2020). Cancer caregivers have been found to be vulnerable to developing depression (Rumpold et al. 2016; Trevino et al. 2018). In some studies, caregivers were more distressed and reported similar to or even higher levels of depression than patients (Kim et al. 2015; Posluszny et al. 2019; Sklenarova et al. 2015). Caregiver burden may be one of the main factors behind increasing the risk of depressive symptoms among cancer caregivers (Geng et al. 2018).

As a potential coping mechanism, spirituality has been discussed as a stress-buffering resource in the relationship between caregiver burden and mental health in the cancer caregiver literature (Fletcher et al. 2012; Weaver and Flannelly 2004). Spirituality is considered an internal factor influencing caregivers' positive outlook and, in turn, making them resilient and impacting emotional balance by decreasing a sense of uncertainty (Duggleby et al. 2010; Hunter-Hernández et al. 2015). In Folkman's modified theoretical model of the coping process,

integrated pathways posit meaning-based processes that lead to positive psychological states; spiritual beliefs/activities may facilitate the reappraisal of stressful caregiving situations by reframing the sufferings of caregivers positively and hopefully (Folkman 1997). Previous reviews have noted that spirituality/religion is a source of optimism and hope that facilitates coping and meaning-making among cancer caregivers (Applebaum et al. 2016; Lalani et al. 2018). In a qualitative study, caregivers considered caregiving as their duty, and they also noted that spirituality provides them strength to perform caregiving activities (Dilworth-Anderson et al. 2007). Spirituality can also give caregivers a sense of indirect control over stressors and acceptance of situations (Koenig 2009). Caregiver spirituality may be positively related to perceived social connectedness due to practical support and encouragement from spiritual/religious communities (Koenig et al. 2016). In experiences of advanced cancer caregivers, ties between religious faith and transcendence, hope, and connectedness were intertwined closely regardless of a strong identification or rejection of religiosity (Wikert et al. 2021).

Similar to the paradigm posited by Reed (1992), US palliative care leaders at the Consensus Conference used the consensus process to define spirituality as the tendency to or the way persons seek meaning through a sense of connectedness within oneself and connectedness with others, nature, and a god/greater power, with the intent to be broad and inclusive of religion (Puchalski et al. 2009, 2014). In addition, based on agreement reached on the definition of spirituality through the European Association for Palliative Care task force (Best et al. 2020; Nolan et al. 2011), it refers to “the dynamic dimension of human life that relates to the way persons experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.” Considering core dimensions in palliative care, spirituality is a multidimensional complex construct, including subcomponents of spiritual/religious beliefs, experiences, and practices (Steinhauser et al. 2017). Research on this construct is hampered by inconsistent definitions and measurements (Reinert and Koenig 2013). When assessing the relationship between spirituality and health outcomes, it is necessary for rigorous research to distinguish spirituality from positive psychological/social status in order to avoid using biased measures of spirituality that are contaminated with mental health concepts (Koenig 2009; Koenig et al. 2012; Steinhauser et al. 2017). If several items assessing good mental states (e.g., positive emotions and general well-being) are included in the measure of spirituality, the constructs of spirituality and mental health will overlap with one another. Furthermore, spirituality is a broader term than religion/religiosity, and religious involvement can be a part of spirituality (Reinert and Koenig 2013; Thoresen and Harris 2002). In this regard, religious involvement is used as a proxy for measuring spirituality in a research context, encompassing constructs including intrinsic religiosity and religious attendance (Koenig et al. 2012). Since caregivers acknowledge the importance of spirituality in caregiving, more studies focusing on religious involvement among cancer caregivers are needed as a priority research area (Delgado-Guay et al. 2013; Lalani et al. 2018; Reinert and Koenig 2013).

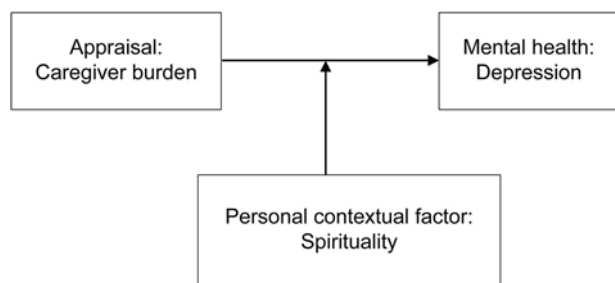
Early reviews noted that higher levels of spirituality are generally associated with better mental health (Hebert et al. 2006; Koenig 2015). However, most of the research on this topic have focused on caregivers of individuals with Alzheimer’s and dementia, used cross-sectional designs and different measures, and shown mixed results (Leblanc et al. 2004; Sun and Hodge 2012; Yoon et al. 2018).

In one study, spirituality reduced the detrimental effects of caregiver burden on depression in Latina Alzheimer’s caregivers (Sun and Hodge 2012), but another study found no moderation effect of stress between perceived religiosity and depression (Leblanc et al. 2004). A few cross-sectional studies support the moderating effects of spirituality among cancer caregivers (Colgrove et al. 2007; Kim et al. 2007). However, to the best of our knowledge, no studies have examined the role of spirituality in caregiver burden–depression using longitudinal data among cancer caregivers.

Research findings of caregiving strain in both cancer and dementia caregivers are also confounded by different disease characteristics, such as disease progression and patients’ needs/symptoms (Kim and Schulz 2008). Cancer caregivers may face relatively rapid progression and more intense therapies compared to dementia caregivers. Given the complexity of cancer treatments and their multiple side effects, more longitudinal studies on caregiving experiences that take spirituality into account are necessary (Wikert et al. 2021). The cancer caregiving trajectory is not likely linear; different demands and burdens may fluctuate independently and frequently (National Academies of Sciences, Engineering, and Medicine 2016). A course of treatment usually takes between 3 and 6 months, during which phase patients have around 4–8 cycles of treatment and underwent adverse changes in quality of life (Cancer Research UK 2020; Roick et al. 2020; Sibeoni et al. 2018). This study focused on caregivers during active cancer treatment, a time where caregivers tend to report more extensive demands than other phases (Northouse et al. 2012).

This study is grounded by the Cancer Family Caregiving Experience Model (Fletcher et al. 2012) that arises from the conceptual work of Lazarus and Folkman (1984) and recent caregiving research. It posits that caregivers’ stress processes influence health/well-being outcomes depending on contextual factors across the cancer trajectory. Spirituality may be a personal contextual characteristic that moderates the stress process (Fletcher et al. 2012). In this sense, according to Park (2013), spirituality is a prime example of a belief system and can inform all aspects of global meaning, providing motivation and goals for living. Stability and personal relevance were identified as attributes of global meaning (Park and Folkman 1997). Using this interpretation, this study selected a measure of general spirituality that can reflect a core aspect of global meaning (i.e., each person’s general orienting systems and views) (Park 2013). It can be seen as a resource that facilitates one’s coping and positive reappraisals of the difficult situation, not primary appraisals (Folkman 1997; Park and Folkman 1997). Considering the meaning-making model (Park and Folkman 1997; Park 2013), spirituality can influence the process of meaning-making as a personal contextual factor.

The stress process component includes stressors (including patient illness-related factors), primary cognitive appraisal (i.e., how individuals evaluate stressors), and health/well-being. As Lazarus and Folkman (1984) noted, health/well-being outcomes depend on how they appraise stressors. The primary cognitive appraisal can explain why stressors may be stressful to some but not to other caregivers. Thus, this study selected caregiver burden as caregiver cognitive appraisal (an individual’s perceptions of stressors) that influences mental health. The cancer trajectory element reflects time regarding stressful events, allowing to explain different phases over the course of cancer. As illustrated in the conceptual framework (Fig. 1), this study proposed the associations between a personal contextual characteristic (i.e., spirituality), caregiver appraisal (i.e., subjective burden), and mental health



**Figure 1.** A conceptual model adapted from the Cancer Family Caregiving Experience Model: Spirituality as a moderator in the association between caregiver burden and depression over time.

(i.e., depression) over the course of the cancer trajectory (i.e., when initiating new cancer treatment over 6 months).

Therefore, the aims of this study were to: (1) explore whether caregiver burden, spirituality, and depression change over time; and (2) examine whether spirituality serves as a moderator that attenuates caregiver burden on depression during a 6-month course of active cancer treatment.

## Methods

### Study design and sample

This longitudinal study was a secondary data analysis of data from a longitudinal project (NCT01981538). The study was conducted at the National Institutes of Health (NIH) Clinical Center from March 2014 to July 2016. Data were collected at the start of a new cancer treatment (T0), 3-month follow-up (T1), and 6-month follow-up after enrollment (T2). A member of the research team initially approached patients to ascertain whether an informal caregiver would be supporting them regularly during their treatment. Caregivers were recruited if they expressed interest in the study and were deemed eligible for study participation. Informed consent was obtained prior to the start of any study-related procedures. Details of the study and a flowchart of caregiver enrollment and participation have been published elsewhere (Klagholz et al. 2018; Ross et al. 2020). The parent study was a feasibility study of a web-based patient-reported outcome collection system focusing on cancer caregivers and was approved by the institutional review board (IRB) of the National Heart, Lung, and Blood Institute. This secondary analysis research used a de-identified dataset recognized by the University of Maryland Baltimore IRB. The convenience sample was composed of family caregivers of cancer patients receiving cancer treatment at the NIH. The caregivers were eligible if they were aged 18 years or over were able to read and speak in English/Spanish, had internet access, and were able to serve as active caregivers through the study. Exclusion criteria included: age of less than 18, inability to read and speak English/Spanish, a paid caregiver, and no computer/internet access. Multiple measures were completed by caregivers via online surveys.

### Measures

Demographic information for caregivers included self-reported age, gender, race/ethnicity, education attainment, annual income, and working status. Caregivers were also asked about their caregiving role (whether they were sole caregivers or part of a caregiving team) and caregiving duration in months. The patient's characteristics gathered via medical records included age, cancer

status (progressive/refractory cancer or others), and hospital status (inpatient or outpatient setting). These potential factors related to depression were included in analyses as covariates: younger caregiver age, female gender, lower socioeconomic status, being unemployed, spousal caregiving, longer duration of caregiving, younger patient age, poor patients' condition/illness progression, and inpatient setting (Geng et al. 2018; Girgis et al. 2013; Pitceathly and Maguire 2003; Rhee et al. 2008; Rivera 2009).

### Caregiver burden

Perceived burden was assessed using the Caregiver Reaction Assessment (CRA) (Given et al. 1992). The CRA consists of 24 items on 5 aspects of caregiving experience: impact on schedule, impact on finances, lack of family support, self-esteem related to caregiving, and impact on health as a result of caregiving. Items are rated using a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree). The score of the caregiver esteem subscale was reversed based on a previous study (Groves et al. 2006), thus higher mean scores indicate a greater sense of caregiver burden, with a range of 1–5. The reliability and validity of the measure have been established in family caregiver research (Given et al. 1992). Cronbach alphas in this sample ranged from 0.70 to 0.92 across the time points.

### Depressive symptoms

Family caregivers' depressive symptoms were assessed using the Patient-Reported Outcomes Measurement Information System (PROMIS®) depression (Cella et al. 2010). Each item is rated on a 5-point Likert scale ranging from 1 (never) to 5 (always). The raw sum scores were converted to standardized T-scores, with a mean of 50 and a standard deviation (SD) of 10 compared to the US general population. Higher T-scores indicate more severe symptoms during the previous week. A T-score of <55 is within normal limits, 55–60 mild, 60–70 moderate, and >70 severe (HealthMeasures, n.d.). The scale has well-established reliability and validity (Cella et al. 2010). The PROMIS® depression was administered as a Computerized Adaptive Test in this study, meaning that the number of items varied (typically 4–7 items) based on individual responses. The assessment automatically stopped when the standard error fell below 0.3 (theta), which corresponds to a reliability of 0.9 (Morris et al. 2020).

### Spirituality

The Spiritual Perspective Scale (SPS) is considered a 10-item questionnaire to assess spirituality defined in the context of spiritual/religious involvement (Reed 1986, 1987; Reinert and Koenig 2013). The SPS is designed to capture general spirituality, addressing cognitive and behavioral expressions of spirituality rather than coping responses (Monod et al. 2011). It measures the extent to which individuals hold certain spiritual beliefs (e.g., "My spiritual views have had an influence upon my life") and engage in spiritual activities (e.g., "How often do you engage in private prayer or meditation") (Monod et al. 2011; Reed 1986, 1987). The instrument uses "spiritual" and "higher power" terminologies in items and avoids confounds with mental health outcomes (Reinert and Koenig 2013). The items of this scale are scored on a 6-point Likert scale, from 1 (not at all/strongly disagree) to 6 (about once a day/strongly agree). A total score is calculated by averaging items and ranges from 1 to 6. Higher mean scores reflect greater levels of spiritual perspectives (i.e., the extent to which spirituality permeates their lives and individuals engage in spiritually related interactions). Reliability and validity of the SPS have been demonstrated

among terminally ill patients and palliative care and caregivers of advanced cancer (La et al. 2020; Reed 1986, 1987; Selman et al. 2011). Two underlying factors have been identified (i.e., spiritual behaviors and beliefs); however, because they are highly correlated to each other ( $r = 0.96$ ), the scale was considered unidimensional (La et al. 2020). In this study, Cronbach alpha was 0.95–0.96 across the 3 time points.

### Data analysis

SPSS 26.0 (SPSS Inc., Chicago, IL) was used for data analysis. Descriptive statistics were used to summarize the characteristics of the sample, and the normality of the measures was checked. Missing data analyses were used to check the randomness of missing values. Little's missing completely at random test ( $p > .05$ ) indicated that missing data were missing completely at random in this sample, which means that the assumption of linear mixed models (LMMs) is met and that the parameter estimation is unbiased in this sample. In another words, the parameter estimation is equivalent with and without dropout in this sample (Molenberghs et al. 1997). For attrition analysis, chi-square tests or t-test was used to compare the baseline characteristics of caregivers who completed a 6-month follow-up with those who did not.

LMMs were used to enable the use of all available data even when dropouts and missing values occur and to accommodate time-varying covariates. The intraclass correlations (ICCs) were greater than 1%, confirming the appropriateness of LMM analyses. First, changes in variables of interest over time were evaluated using unconditional growth models that include only time as a predictor. Second, the association between burden and depression and the moderating effect of spirituality on the association were examined using LMM. Three-level LMMs with random intercept

were used to deal with repeated measures of depression over time (level 1), sampled from caregivers (level 2), and nested within patients (level 3). Depression was a dependent variable, and ICCs were estimated as 0.37 for level 2 and 0.21 for level 3. The models contained time, burden, spirituality, and interactions between these variables. To control for the effects of caregiver and patient characteristics, covariates were entered into the models, and working status and hospital status were time-variant covariates. For post hoc analyses, separate sets of LMM models were implemented depending on each burden subscale to check difference in the magnitude of the interaction effects. To obtain parsimonious models with the best fit by comparing across models, Akaike Information Criterion (AIC) and Bayesian Information Criterion (BIC) were used. Smaller AIC and BIC values indicate better models.

### Results

Due to attrition, the number of caregivers decreased from 129 at baseline to 93 at 3 months, and 65 remained at 6 months. No statistically significant differences in baseline characteristics were found between caregivers who completed the follow-ups and those who did not, other than cancer status. More caregivers of patients with progressive/refractory cancer tended to drop out than caregivers of other cancer status ( $X^2 = 4.931, p = .026$ ). Caregivers of patients who did not have progressive/refractory cancer tended to provide full data across time.

### Sample characteristics

Information related to caregivers and patients at baseline is summarized in Table 1. The mean age of caregivers was  $48.58 \pm 11.77$ . Out of all the caregivers, 67.4% were female, and

**Table 1.** Baseline characteristics of the sample and according to whether caregivers dropped out

		Total	Dropped out		Comparison <sup>a</sup>	
			No	Yes		
Caregiver characteristics (n = 129)		M ± SD/ n (%)	M ± SD/ n (%)	M ± SD/ n (%)	t/X <sup>2</sup>	p
Age in years	Range: 20–76	48.58 ± 11.77	49.62 ± 12.10	47.53 ± 11.42	1.006	.316
Gender	Female	87 (67.4)	43 (49.4)	44 (50.6)	.099	.753
	Male	42 (32.6)	22 (52.4)	20 (47.6)		
Marital status	Married	107 (83.6)	55 (51.4)	52 (48.6)	.513	.474
	Nonmarried	21 (16.4)	9 (42.9)	12 (57.1)		
Relationship to patient	Spouses/partners	64 (49.6)	34 (53.1)	30 (46.9)	2.131	.345
	Parents	45 (34.9)	19 (42.2)	26 (57.8)		
	Others	20 (15.5)	12 (60.0)	8 (40.0)		
Race/ethnicity	Non-Hispanic/White	91 (71.1)	45 (49.5)	46 (50.5)	.064	.969
	Hispanic/Latino	19 (14.8)	10 (52.6)	9 (47.4)		
	Non-White/Non-Hispanic	18 (14.1)	9 (50.0)	9 (50.0)		
Religious affiliation	Having religion <sup>b</sup>	115 (91.3)	57 (49.6)	58 (50.4)	.795	.372
	No affiliation	11 (8.7)	7 (63.6)	4 (36.4)		
Education level	Bachelor's degree/below <sup>c</sup>	85 (65.9)	44 (51.8)	41 (48.2)	.189	.664
	Graduate/professional	44 (34.1)	21 (47.7)	23 (52.3)		

(Continued)

Table 1. (Continued.)

		Dropped out			Comparison <sup>a</sup>	
		Total	No	Yes	<i>t</i> / <i>X</i> <sup>2</sup>	<i>p</i>
		<i>M</i> ± <i>SD</i> / <i>n</i> (%)	<i>M</i> ± <i>SD</i> / <i>n</i> (%)	<i>M</i> ± <i>SD</i> / <i>n</i> (%)		
<b>Caregiver characteristics (n = 129)</b>						
Annual income <sup>d</sup>	<\$50,000	35 (29.2)	16 (45.7)	19 (54.3)	.701	.402
	≥\$50,000	85 (70.8)	46 (54.1)	39 (45.9)		
Employment status	Working	95 (73.6)	48 (50.5)	47 (49.5)	.003	.958
	Not working	34 (26.4)	17 (50.0)	17 (50.0)		
Caregiving role	Sole caregiver	59 (45.7)	34 (57.6)	25 (42.4)	2.280	.131
	Part of team	70 (54.3)	31 (44.3)	39 (55.7)		
Caregiving duration	Median (IQR)	18 (5.0, 37.6)			3.011	.083
<b>Care-recipient characteristics (n = 111)</b>						
Age in years	<18 (range: 4 – 17)	14 (12.6)	6 (35.3)	11 (64.7)	1.784	.182
	≥18 (range: 18 – 76)	97 (87.4)	59 (52.7)	53 (47.3)		
Gender	Female	50 (45.0)	34 (55.7)	27 (44.3)	1.325	.250
	Male	61 (55.0)	31 (45.6)	37 (54.4)		
Cancer type <sup>e</sup>	Solid tumor	75 (67.6)	45 (51.1)	43 (48.9)	.062	.803
	Hematologic cancer	36 (32.4)	20 (48.8)	21 (51.2)		
Cancer status	Progressive/refractory	89 (80.2)	48 (45.7)	57 (54.3)	4.931	.026*
	Other	22 (19.8)	17 (70.8)	7 (29.2)		
Treatment type	Single therapy <sup>f</sup>	23 (20.7)	16 (61.5)	10 (38.5)	3.153	.207
	Bio/immunotherapy	69 (62.2)	37 (44.6)	46 (55.4)		
	Combination therapy <sup>g</sup>	19 (17.1)	12 (60.0)	8 (40.0)		
Hospital status	Inpatient	92 (83.6)	51 (47.7)	56 (52.3)	1.424	.233
	Outpatient	18 (16.4)	13 (61.9)	8 (38.1)		

IQR = interquartile range; *M* = mean; *SD* = standard deviation.

\**p* < .05. Totals vary due to missing data.

<sup>a</sup>*t*-test for continuous variables and chi-square test for categorical variables between caregivers who were dropouts and completers.

<sup>b</sup>Christian (*n* = 97): Catholic (*n* = 43), Protestant (*n* = 43), non-denominational/other (*n* = 11), Jewish (*n* = 9), Other (*n* = 9) (e.g., Muslim and Buddhist).

<sup>c</sup>Less than high school (*n* = 4), high-school graduate (*n* = 3), some college or associate's degree (*n* = 43), and Bachelor's degree (*n* = 35).

<sup>d</sup>Less than \$10,000 (*n* = 13), \$10,000–29,999 (*n* = 6), \$30,000–49,999 (*n* = 16), \$50,000–69,999 (*n* = 12), \$70,000–89,999 (*n* = 16), \$90,000–149,000 (*n* = 30), and greater than \$150,000 (*n* = 27).

<sup>e</sup>Carcinoma (*n* = 52): prostate, melanoma, anal, breast, lung, colon, liver, cervical, ovarian, adrenal cortical, pancreatic, kidney, thymus, thyroid, and peritoneal cancer; leukemia (*n* = 25): chronic myelogenous leukemia, acute lymphocytic leukemia, acute myelogenous leukemia, and chronic lymphocytic leukemia; sarcoma (*n* = 23): brain, gastrointestinal stromal tumor, and desmoid tumors; lymphoma (*n* = 10): Hodgkin's and non-Hodgkin's lymphoma; and myeloma (*n* = 1): multiple myeloma.

<sup>f</sup>Chemotherapy (*n* = 10), radiation (*n* = 3), and surgery (*n* = 10).

<sup>g</sup>Hematopoietic stem cell transplantation (*n* = 11) and other (*n* = 8).

71.1% were non-Hispanic Whites. The majority of caregivers were married (82.9%) and reported some religious affiliation (89.1%). Relationship to the patient included spouses/partners (49.6%), parents (34.9%), adult children (7.8%), and others (7.8%). These participants were relatively highly educated, with 34.1% having gone to graduate/professional school. Most (73.6%) were employed either part- or full-time, and 70.8% had annual household incomes of ≥ \$50,000. The median duration of caregiving was 18 months, and 45.7% perceived that they were sole caregivers.

Most patients (87.4%) were aged 18 years and older, and 45% were females. Patients had a variety of cancer types consisting of 68.5% solid and 31.5% hematologic cancers. Approximately 80% of patients had progressive/refractory cancer, 62.2% received bio/immunotherapy, and 83.6% were initially admitted for treatment.

### Caregiver burden, spirituality, and depression score across time

The variables of interest at 3 time points over the course of the study are presented in Table 2; all were normally distributed. On average, depression scores ranged from 51.36 ± 8.77 to 52.47 ± 7.70; at baseline, 32.6% of caregivers reported at least mild symptoms; 30.1% at 3 months; and 32.8% at 6 months. In unconditional growth models, average spirituality (0.013, *p* = .194) and depression (0.099, *p* = .502) scores showed a stable pattern over time. As reported previously (La et al. 2021), caregiver total burden scores did not change significantly over time. Similar results were observed, and statistical significance was maintained from additional analyses after adjusting for caregiving duration.

**Table 2.** Mean and standard deviations of baseline, 3-months, and 6-month follow-up scores for study variables and changes over time

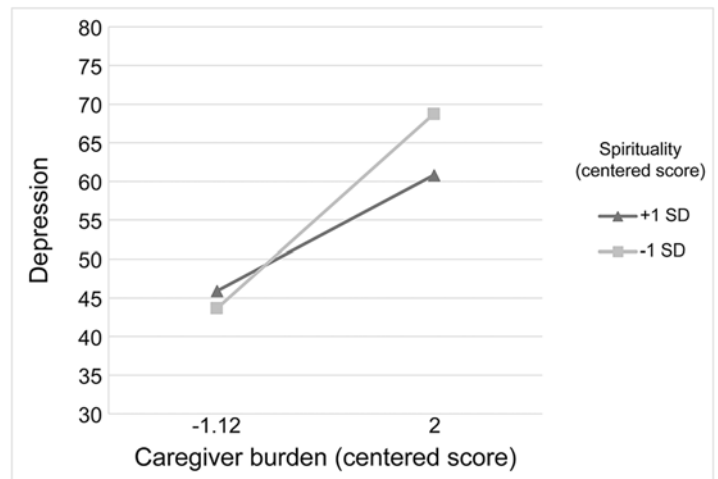
Variables	Baseline (T0)			3 months (T1)			6 months (T2)			Estimate	p
	M ± SD	Range		M ± SD	Range		M ± SD	Range			
Spirituality	4.47 ± 1.35	1.00–6.00		4.61 ± 1.32	1.00–6.00		4.51 ± 1.49	1.00–6.00		0.013	.194
Caregiver burden											
Total burden	2.30 ± 0.50	1.17–4.29		2.28 ± 0.57	1.08–4.00		2.28 ± 0.67	1.00–4.04		-0.003	.670
Impact on schedule	3.45 ± 0.86	1.00–5.00		3.27 ± 0.93	1.00–5.00		3.09 ± 0.98	1.00–5.00		-0.043	.001*
Impact on finances	2.81 ± 1.15	1.00–5.00		2.78 ± 1.13	1.00–5.00		2.75 ± 1.14	1.00–5.00		-0.021	.123
Impact on health	2.17 ± 0.75	1.00–5.00		2.11 ± 0.83	1.00–4.50		2.07 ± 2.07	1.00–4.75		-0.006	.592
Lack of family support	1.86 ± 0.75	1.00–4.40		1.96 ± 0.80	1.00–4.60		2.07 ± 0.88	1.00–5.00		0.020	.080
Lack of caregiving esteem	1.63 ± 0.51	1.00–3.43		1.70 ± 0.61	1.00–3.43		1.76 ± 0.66	1.00–3.71		0.018	.022*
Depression (T-score)	52.47 ± 7.70	34.17–81.83		51.36 ± 8.77	34.17–79.76		51.79 ± 8.06	34.16–69.45		-0.099	.502

M = mean; SD = standard deviation. Depression was assessed with the PROMIS depression (range, 20–80); caregiver burden was assessed with the Caregiver Reaction Assessment (range, 1–5); spirituality was assessed with the Spiritual Perspective Scale (range, 1–6).  
\*p < .05.

**Table 3.** Parsimonious linear mixed models to examine the contribution of burden to depression according to the levels of spirituality over time

Outcome: Depression	Total burden model			Burden subscale model			Impact on health		
	Estimate	p		Estimate	p		Estimate	p	
Intercept	26.49	<.001		33.49	<.001		41.08	<.001	
Time	-0.34	.113		-0.31	.177		-0.34	.127	
Burden	12.70	<.001		7.51	<.001		6.14	<.001	
Spirituality	2.65	.061		2.02	.160		1.98	.060	
Burden × Time							0.47	.013	
Spirituality × Time							0.21	.055	
Burden × Spirituality	-1.35	.015		-0.92	.023		-1.07	.001	
Lack of family support							52.47	<.001	
Lack of caregiving esteem							-2.34	.002	
Impact on schedule							33.49	<.001	
Impact on finances							6.14	<.001	
Lack of caregiving esteem							55.85	<.001	
Impact on health							-0.42	.059	
Estimate							3.31	.001	
p							-0.83	.089	
Estimate							48.49	<.001	
p							-0.21	.321	
Estimate							4.64	<.001	
p							-1.09	.011	

The PROMIS depression was used as an outcome measure for all models. Data were analyzed with the use of separate models, adjusted for caregiver age, gender, race/ethnicity, education, income, working status (time-varying), caregiving role, relationship to patient, caregiving duration, patient age, cancer status, and hospital status (time-varying).



**Figure 2.** Interaction between total caregiver burden and spirituality on depression at baseline. Scores are plotted at the mean  $\pm$  1 standard deviation (SD) for spirituality. Higher scores indicate greater burden and depression.

### Tests of moderation analysis

As shown in Table 3, no three-way interaction among variables of interest existed. In the final model of depression, a main effect of total caregiver burden on depression remained statistically significant (12.70,  $p < .001$ ), controlling for characteristics of caregivers and patients. Greater levels of total burden were associated with higher levels of depression. There was a significant interaction between spirituality and total burden ( $-1.35$ ,  $p = .015$ ), indicating that spirituality moderated the relationship between total caregiver burden and depression over time. In other words, when caregivers had higher levels of spirituality, the effect of total burden on depression tended to decrease. Or when caregiver burden is higher, caregivers' spirituality has more impact on their depression. Figure 2 illustrates the regression of depression on total burden at low ( $-1$  SD below the mean) and high ( $+1$  SD above the mean) levels of spirituality as a continuous moderator variable. A steeper slope was detected for caregivers who reported lower spirituality than for those who reported higher spirituality (i.e., the relationship was stronger for caregivers with lower spirituality than those with higher spirituality).

In terms of burden subdomains, all subscales were predictive of depression in the same direction as the main effect of total burden. Results also revealed significant moderating effects of spirituality on the relationship between burden subscales (except for lack of caregiving esteem and impact on health) and depression over time. Namely, the effects of perceived schedule burden ( $-0.92$ ,  $p = .023$ ), financial burden ( $-1.07$ ,  $p = .001$ ), and lack of support burden ( $-0.77$ ,  $p = .043$ ) on depression were weaker among caregivers with higher spirituality than among those with lower spirituality. In addition, among burden subscales, only the association between lack of family support and depression changes over time ( $0.47$ ,  $p = .013$ ). That is, depression scores increased over time for caregivers who had higher levels of lack of family support. Modeling of additional patient characteristics (types of cancer and treatment) did not alter patterns of results and the statistical significance.

### Discussion

In this study, we found that caregiver burden, spirituality, and depression were stable over the 6-month treatment period;

however, the relationship between burden and depression is different at different levels of spirituality. It demonstrates that the relationship between burden and depression is positive, but it is far more so for caregivers with lower spirituality than for those with higher spirituality. Our finding that spirituality appears to buffer the effects of caregiver burden on depression over the course of cancer treatment is novel.

This finding indicates that spirituality may be a stable personal contextual characteristic of cancer caregivers during the period of active treatment. It is consistent with a longitudinal study of caregivers of patients with malignant brain tumors, which conceptualized spirituality as a personal characteristic and considered spirituality as relatively stable over 8 months after diagnosis (Newberry et al. 2013). Similarly, in Fife et al.'s (2009) study of cancer caregivers of bone marrow transplantation (BMT) recipients, caregivers' levels of spirituality were consistent during the acute phase of the BMT period. According to Wikert et al.'s (2021) qualitative study of advanced cancer caregivers, their narratives demonstrated an ongoing spiritual experience from diagnosis to bereavement. In the analyzed narratives, spirituality appeared as a perceived connectedness and religious faith that ties religious community, belief structure, and transcendence. As spirituality is central in many individuals' meaning systems related to beliefs, motivation, and goals (Park 2013), it is required to clarify its characteristics in caregiving. Hence, how changes in specific aspects of spirituality happen warrant further long-term investigation, considering the time before/right after diagnosis and diverse religious/spiritual groups.

In this study, caregiver burden reflected this sample's perceived care demand. Unlike those in academic/community hospitals, individuals seek to enter NIH clinical trials to receive novel treatments not readily available anywhere else. For several weeks, caregivers "uproot and relocate" themselves to be near the NIH Clinical Center. Life disruption, loss of daily routines, arranging work/home/other responsibilities, and relevant travel, lodging, and meal costs are among the many challenging problems these caregivers must face (Rezash et al. 2020; Vindrola-Padros et al. 2018). This may affect scores on the schedule and financial burden dimensions, which were higher than those of other caregivers (Mazanec et al. 2011; Rezash et al. 2020). More attention needs to be paid to understand the impact of traveling and relocation on caregiving.

In addition, in the present study, almost one-third of caregivers had depressive symptoms over time (T-score of  $\geq 55$  links with the cutoff point for possible clinical depression from the legacy measures) (Choi et al. 2014). Although overall mean depression scores fell within the normal range, this sample of caregivers of patients reported higher mean scores at baseline ( $52.47 \pm 7.70$ ) than that of caregivers of patients with stage III/IV breast cancer receiving chemotherapy/hormonal therapy in the United States ( $45.14 \pm 6.97$ ) (Sikorskii et al. 2018). Perhaps because in this study caregivers were caring for patients who participated in clinical trials at the NIH due to therapy for progressive, treatment-refractory, or rare cancer and who were likely to have severe symptoms and a decline of functional status. In addition, cancer caregivers could face anticipatory grief for terminally ill relative, leading to an additional negative impact on psychological health (Coelho et al. 2020). A study comparing differences between advanced cancer caregivers in active treatment and hospice care found no significant differences in caregiver burden (Spatuzzi et al. 2017). Yet, compared to the active treatment settings, the hospice group reported significantly poorer mental health and better physical health. Considering palliative care throughout the continuum of cancer, further research should be extended beyond 6 months of follow-up to explain differences in caregiving trajectories.

Moreover, in this study, caregivers' depression did not change significantly, indicating that caregivers tend to maintain the level of depression they had at baseline over time, on average. This may be explained by continuous stressors related to treatments for cancer and high concerns about future over time, which is related to depression among family caregivers of advanced cancer patients (Sato et al. 2021). This period is a time of stress and concerns for caregivers. In particular, despite attrition, participants in this study were caregivers of patients who had cancer for which there is a lack of standardized treatment approach or no standard of care treatment is exist. During the treatment, they face uncertainty, worry about the efficacy, and concerns for toxic side effects, patients' decline, and death (Rezash et al. 2020). Similarly, in a previous study of cancer caregivers, depressive symptom scores were sustained during active treatment (Stenberg et al. 2014). In contrast, in a study of caregivers of patients with newly diagnosed, untreated head and neck cancer (55% stage 3 or 4), the severity of depression significantly decreased over 6 months (Lee et al. 2017). This inconsistent pattern in depression could be attributed to different sample characteristics or study design. Since very few longitudinal studies of advanced cancer caregiver depression exist (Bedaso et al. 2022), more studies are needed to draw conclusion.

The novelty of this study is to use spirituality as a moderator that could hold promise for providing holistic care for cancer caregivers. The most notable finding in this study was interactions between caregiver burden and spirituality in predicting depression. Even after controlling for covariates, this study suggested that caregivers' spirituality buffered the effects of total caregiver burden on depression over the course of cancer treatment. This finding is similar to cross-sectional studies of cancer caregivers showing beneficial effects of spirituality on diminishing the impact of caregiving stress on emotional distress and mental health (Colgrove et al. 2007; Kim et al. 2007; Ochoa et al. 2020). In caregiver studies, spirituality is viewed as a resource for promoting resilience (Lin et al. 2013). Furthermore, caregivers' sustained burden and depression are likely to negatively influence their own physical health and patients' depression over time (Kershaw et al. 2015; Kurtz et al. 2004). Consequently, spiritual care for cancer caregivers could help in alleviating their own negative psychological

sequelae of caregiving, thus leading to better overall health for both caregivers and individuals with cancer. With regard to research, several pathways of spirituality/religiousness influence on health outcomes have been proposed (Fletcher et al. 2012; Folkman 1997; Park 2013). However, much remains to be learned, and it is difficult to keep spiritual/religious factors conceptually distinct (Park 2007). So, specific components of spiritual dimensions, including positive reappraisal, should be considered for testing these complex pathways and meaning-making process using validated measures within theoretical framework for future caregiving research.

It is the first approach in advancing our understanding of the impact of spirituality by addressing various aspects of cancer caregiver burden using longitudinal data. Given the multidimensional nature of caregiver burden, the interaction between each burden subscale and spirituality may vary. Caregiver burden as cognitive appraisal refers to a subjective experience in which the caregivers perceive adverse effects related to social life, financial status, and health resulting from caregiving (Zarit et al. 1986). Interestingly, results revealed that moderation effects of spirituality differed for each burden subscale. The magnitude of the relationship was stronger for total burden than that for the subscales; caregivers' spirituality buffers the caregiver burden subscale-depression association, especially in the aspect of schedule burden, financial burden, and lack of family support. Our findings suggest that greater spirituality protects a caregiver effectively from feeling depressed, particularly when these 3 aspects of burden increase. It seems likely that caregivers can access support sources and enhance social connectedness through involvement in religious/spiritual community and spiritual activities (LeSeure and Chongkham-Ang 2015; Weaver and Flannelly 2004).

On the other hand, spirituality may not be an impactful factor in reducing the influence of the perception of a lack of caregiver esteem and health related to caregiving on depression. The associations between 2 burden subscales (lack of caregiver esteem and impact of caregiving on health) and depression were similar across caregivers, regardless of their level of spirituality. These different patterns of moderating effects of spirituality on the relationship between the sub-dimensions of burden and depression may provide insight into the underlying conditions and help to better target interventions to support caregivers. Apart from spirituality, objective caregivers' health status (e.g., number of comorbidities) and other factors (e.g., caregiving mastery and relationship quality between patients and caregivers) could influence this relationship (Fletcher et al. 2012; Pioli 2010; Schumacher et al. 2007).

The findings have implications for family caregivers of cancer patients, as well as the clinical and nonclinical support services. Clinicians are encouraged to be attentive and perhaps screen early and often for caregiver burden, spirituality, and depressive symptoms. While spirituality matters are often considered the domain of chaplains in hospitals, clinicians have continuous contact with cancer caregivers, so they need to discern and respond to their spiritual needs. As a first step, it is crucial to perform spiritual screenings for cancer caregivers when planning treatments to maximize a personal coping resource and provide best spiritual care. At other points along the treatment trajectory, caregivers may suffer from religious/spiritual struggles and concerns, including questions of meaning, a sense of guilt, and a sense of punishment and abandonment by God due to cancer (Sprik et al. 2021). Not only favorable functions but also sufferings underscore the importance of spiritual assessment and support for caregivers. In cancer care, formal spiritual screenings may be appropriate and easily integrated into care processes and electronic health records as a part of



the routine comprehensive evaluation. However, nurses/physicians tended to perceive barriers in spiritual care provision, including lack of training, lack of time/space, and role conflict (Balboni *et al.* 2014). Thus, clinicians need to be trained to conduct inclusive spiritual care and screening for families with diverse cultural, religious, and social backgrounds and to make referrals to suitable spiritual care providers (Puchalski *et al.* 2009). All clinicians should understand spiritual/cultural diversity and have competence for spiritual care. Many cancer care teams have chaplains/other spiritual care providers, who can be valuable resources. Cancer care teams also need to provide families with information about chaplaincy services, spiritual spaces (such as chapels, prayer/meditation rooms, and gardens), and online resources, including support groups and prayer requests.

Taking into consideration family caregivers' religious/spiritual preferences, this study points to the necessity of efforts to collaborate with spiritual/religious organizations in the community. Families of cancer patients should be encouraged to take advantage of the services available in their congregations. Likewise, other resources may also provide support, including spiritual support groups and psychosocial interventions to promote meaning (Balboni *et al.* 2017). Such meaning-based interventions focus on relaxation, cognitive restructuring, upholding hope, and exploring priorities for the future (Park *et al.* 2019). For informal caregivers of patients with advanced cancer, there is a wide spectrum of spirituality-integrated interventions, including chaplain visits using a Spiritual Care Assessment and Intervention framework, mindfulness, meditation, existential issues, personal meaning and purpose, and prayers found in research (Perez *et al.* 2022; Zheng *et al.* 2021). Since palliative care is an approach to provide support and to improve quality of life for families along the cancer care continuum regardless of prognosis, the spiritual care implementation model for inpatient/outpatient setting and the National Consensus Project for Quality Palliative Care guidelines are useful to integrate spiritual care into care process and to support caregivers (Puchalski *et al.* 2009).

### Limitations

A strength of this study is the longitudinal design of cancer caregivers that allows to corroborate trajectories and cause-effect relationships using time-varying variables whose value can change over the duration of follow-up. Several potential covariates were included in the analysis. Nonetheless, some limitations of this study should be noted. This study used a convenience sample of cancer caregivers, which can influence findings and generalizability. This sample of family caregivers recruited from the NIH Clinical Center were likely with severely ill patients participating in novel cancer treatment trials for which there is no standardized treatment approach. Caregivers were mostly non-Hispanic White and were affiliated with Christianity. Furthermore, they had a relatively higher socioeconomic status, which may affect their ability to relocate for treatment and to access resources provided by the NIH Clinical Center. More investigations are needed using representative caregiver samples from multiple sites, including diverse socioeconomic and cultural/religious backgrounds. Second, although this study of adult caregivers controlled for covariates, including patients' age, it remains unclear how trajectories in caring for adults versus children differ from each other, thus further exploration could be conducted.

Third, since existing tools conceptualize spirituality in different ways, the SPS in this study may not fully reflect other

spiritual domains, including spiritual coping, pain/distress, and needs. Further work is needed to compare and clarify multiple distinct dimensions of spirituality using other measures' subscales, including the Duke University Religion Index, the Brief Multidimensional Measure of Religiousness/Spirituality, and the Brief Measure of Religious Coping (Koenig 2012; Steinhauer *et al.* 2017).

Fourth, imperfect data are common to secondary analyses and may influence findings. The attrition over time could result in underestimated results of the impact of caregiving. Since it was found that caregivers who did not complete the last follow-up tended to be a caregiver of patients with progressive/resistant cancer, it may be that the patients died or were no longer in active treatment. Caution is required when interpreting results, and the dropout process in palliative care is taken into account. Finally, while this study controlled for some caregiver and patient characteristics, other factors, including health status and symptoms, could not be considered. Furthermore, the parent study included different cancer types and stages. Caregiving research with varying patient factors may be underpowered to detect cancer-specific effects (Kent *et al.* 2019; Streck *et al.* 2020). Future longitudinal caregiver studies of sufficient sample size are needed to provide further insight into unique aspects of caregiving according to cancer type and stage and treatment factors.

### Conclusion

This study adds to the body of literature examining the longitudinal association among caregiver burden, spirituality, and depression during active treatment. The change patterns we found indicate that if the levels of depressive symptoms and burden, as well as spirituality, were high at the beginning, it continues during the treatment period. Given the patterns of changes, this study highlights the importance of early identification of caregivers high on burden or low on spirituality to reduce depression related to detrimental effects of caregiving. The results also showed that total caregiver burden and various dimensions of burden influence depression. As an important resource, spirituality plays a role in moderating caregiver burden-depression association over time. To enhance coping and reduce the negative influence of caring on caregivers' mental health, this information should be taken into account when considering developing caregiver support programs.

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### References

- Adelman RD, Tmanova LL, Delgado D, *et al.* (2014) Caregiver burden: A clinical review. *JAMA* 311(10), 1052–1060. doi:10.1001/jama.2014.304
- Alam S, Hannon B and Zimmermann C (2020) Palliative care for family caregivers. *Journal of Clinical Oncology* 38(9), 926–936. doi:10.1200/JCO.19.00018
- American Cancer Society (2020) Cancer facts & figures 2020. *American Cancer Society*. <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2020/cancer-facts-and-figures-2020.pdf> (accessed 21 October 2020).
- Applebaum AJ, Kryza-Lacombe M, Buthorn J, *et al.* (2016) Existential distress among caregivers of patients with brain tumors: A review of the literature. *Neuro-oncology Practice* 3(4), 232–244. doi:10.1093/nop/npv060

- Balboni TA, Fitchett G, Handzo GF, et al.** (2017) State of the science of spirituality and palliative care research part II: Screening, assessment, and interventions. *Journal of Pain and Symptom Management* **54**(3), 441–453. doi:10.1016/j.jpainsymman.2017.07.029
- Balboni MJ, Sullivan A, Enzinger AC, et al.** (2014) Nurse and physician barriers to spiritual care provision at the end of life. *Journal of Pain and Symptom Management* **48**(3), 400–410. doi:10.1016/j.jpainsymman.2013.09.020
- Bedaso A, Dejenu G and Duko B** (2022) Depression among caregivers of cancer patients: Updated systematic review and meta-analysis. *Psycho-Oncology* **31**(11), 1809–1820. doi:10.1002/pon.6045
- Best M, Leget C, Goodhead A, et al.** (2020) An EAPC white paper on multi-disciplinary education for spiritual care in palliative care. *BMC Palliative Care* **19**, 1–10. doi:10.1186/s12904-019-0508-4
- Cancer Research UK** (2020) Your chemotherapy plan. <https://www.cancerresearchuk.org/about-cancer/treatment/chemotherapy/planning/your-chemotherapy-plan> (accessed 1 October 2020).
- Cella D, Riley W, Stone A, et al.** (2010) The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. *Journal of Clinical Epidemiology* **63**(11), 1179–1194. doi:10.1016/j.jclinepi.2010.04.011
- Choi SW, Schalet B, Cook KF, et al.** (2014) Establishing a common metric for depressive symptoms: Linking the BDI-II, CES-D, and PHQ-9 to PROMIS depression. *Psychological Assessment* **26**(2), 513–527. doi:10.1037/a0035768
- Coelho A, de Brito M, Teixeira P, et al.** (2020) Family caregivers' anticipatory grief: A conceptual framework for understanding its multiple challenges. *Qualitative Health Research* **30**(5), 693–703. doi:10.1177/1049732319873330
- Colgrove LA, Kim Y and Thompson N** (2007) The effect of spirituality and gender on the quality of life of spousal caregivers of cancer survivors. *Annals of Behavioral Medicine* **33**(1), 90–98. doi:10.1207/s15324796abm3301\_10
- Delgado-Guay MO, Parsons HA, Hui D, et al.** (2013) Spirituality, religiosity, and spiritual pain among caregivers of patients with advanced cancer. *American Journal of Hospice and Palliative Medicine* **30**(5), 455–461. doi:10.1177/1049909112458030
- Dilworth-Anderson P, Boswell G and Cohen MD** (2007) Spiritual and religious coping values and beliefs among African American caregivers: A qualitative study. *Journal of Applied Gerontology* **26**(4), 355–369. doi:10.1177/0733464807302669
- Duggleby W, Holtslander L, Kylma J, et al.** (2010) Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research* **20**(2), 148–158. doi:10.1177/1049732309358329
- Fife BL, Monahan PO, Abonour R, et al.** (2009) Adaptation of family caregivers during the acute phase of adult BMT. *Bone Marrow Transplantation* **43**(12), 959–966. doi:10.1038/bmt.2008.405
- Fletcher BS, Miaskowski C, Given B, et al.** (2012) The cancer family caregiving experience: An updated and expanded conceptual model. *European Journal of Oncology Nursing* **16**(4), 387–398. doi:10.1016/j.ejon.2011.09.001
- Folkman S** (1997) Positive psychological states and coping with severe stress. *Social Science & Medicine* **45**(8), 1207–1221. doi:10.1016/S0277-9536(97)00040-3
- Geng H-M, Chuang D-M, Yang F, et al.** (2018) Prevalence and determinants of depression in caregivers of cancer patients: A systematic review and meta-analysis. *Medicine* **97**(39), e11863–e11863. doi:10.1097/MD.00000000000011863
- Girgis A, Lambert S, Johnson C, et al.** (2013) Physical, psychosocial, relationship, and economic burden of caring for people with cancer: A review. *Journal of Oncology Practice* **9**(4), 197–202. doi:10.1200/JOP.2012.000690
- Given CW, Given B, Stommel M, et al.** (1992) The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing & Health* **15**(4), 271–283. doi:10.1002/nur.4770150406
- Grov EK, Fossa SD, Sorebo O, et al.** (2006) Primary caregivers of cancer patients in the palliative phase: A path analysis of variables influencing their burden. *Social Science & Medicine* **63**(9), 2429–2439. doi:10.1016/j.socscimed.2006.06.008
- HealthMeasures** (n.d.) HealthMeasures. PROMIS® Score Cut Points. <http://www.healthmeasures.net/score-and-interpret/interpret-scores/promis/promis-score-cut-points> (accessed 1 October 2020).
- Hebert RS, Weinstein E, Martire LM, et al.** (2006) Religion, spirituality and the well-being of informal caregivers: A review, critique, and research prospectus. *Aging and Mental Health* **10**(5), 497–520. doi:10.1080/13607860600638131
- Hunter-Hernández M, Costas-Muñoz R and Gany F** (2015) Missed opportunity: Spirituality as a bridge to resilience in Latinos with cancer. *Journal of Religion and Health* **54**(6), 2367–2375. doi:10.1007/s10943-015-0020-y
- Kent E, Mollica M, Buckenmaier S, et al.** (2019) The characteristics of informal cancer caregivers in the United States. *Seminars in Oncology Nursing* **35**(4), 328–332. doi:10.1016/j.soncn.2019.06.002
- Kershaw T, Ellis K, Yoon H, et al.** (2015) The interdependence of advanced cancer patients' and their family caregivers' mental health, physical health, and self-efficacy over time. *Annals of Behavioral Medicine* **49**(6), 901–911. doi:10.1007/s12160-015-9743-y
- Kim Y and Schulz R** (2008) Family caregivers' strains: Comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health* **20**(5), 483–503. doi:10.1177/0898264308317533
- Kim Y, van Ryn M, Jensen RE, et al.** (2015) Effects of gender and depressive symptoms on quality of life among colorectal and lung cancer patients and their family caregivers. *Psycho-Oncology* **24**(1), 95–105. doi:10.1002/pon.3580
- Kim Y, Wellisch DK, Spillers RL, et al.** (2007) Psychological distress of female cancer caregivers: Effects of type of cancer and caregivers' spirituality. *Supportive Care in Cancer* **15**(12), 1367–1374. doi:10.1007/s00520-007-0265-4
- Klagholz SD, Ross A, Wehrlen L, et al.** (2018) Assessing the feasibility of an electronic patient-reported outcome (ePRO) collection system in caregivers of cancer patients. *Psycho-Oncology* **27**(4), 1350–1352. doi:10.1002/pon.4658
- Koenig HG** (2009) Research on religion, spirituality, and mental health: A review. *The Canadian Journal of Psychiatry* **54**(5), 283–291. doi:10.1177/070674370905400502
- Koenig HG** (2012) *Spirituality and Health Research: Methods, Measurements, Statistics, and Resources*. PA: Templeton Press.
- Koenig HG** (2015) Religion, spirituality, and health: A review and update. *Advances in Mind-Body Medicine* **29**(3), 19–26.
- Koenig HG, King D and Carson VB** (2012) *Handbook of Religion and Health*, 2nd edn. New York, NY: Oxford University Press.
- Koenig HG, Nelson B, Shaw SF, et al.** (2016) Religious involvement and adaptation in female family caregivers. *Journal of the American Geriatrics Society* **64**(3), 578–583. doi:10.1111/jgs.13929
- Kurtz ME, Cleo Kurtz J, Given CW, et al.** (2004) Depression and physical health among family caregivers of geriatric patients with cancer—a longitudinal view. *Medical Science Monitor* **10**(8), CR447–CR456.
- La IS, Johantgen M, Storr CL, et al.** (2020) Spirituality among family caregivers of cancer patients: the spiritual perspective scale. *Research in Nursing and Health* **43**(4), 407–418. doi:10.1002/nur.22044
- La IS, Johantgen M, Storr CL, et al.** (2021) Caregiver burden and related factors during active cancer treatment: A latent growth curve analysis. *European Journal of Oncology Nursing* **52**, 101962. doi:10.1016/j.ejon.2021.101962
- Lalani N, Duggleby W and Olson J** (2018) Spirituality among family caregivers in palliative care: An integrative literature review. *International Journal of Palliative Nursing* **24**(2), 80–91. doi:10.12968/ijpn.2018.24.2.80
- Lazarus RS and Folkman S** (1984) *Stress, Appraisal, and Coping*. New York: Springer Publishing Company.
- Leblanc AJ, Driscoll AK and Pearlin LI** (2004) Religiosity and the expansion of caregiver stress. *Aging and Mental Health* **8**(5), 410–421. doi:10.1080/13607860410001724992
- Lee C-Y, Lee Y, Wang L-J, et al.** (2017) Depression, anxiety, quality of life, and predictors of depressive disorders in caregivers of patients with head and neck cancer: A six-month follow-up study. *Journal of Psychosomatic Research* **100**, 29–34. doi:10.1016/j.jpsychores.2017.07.002
- LeSeure P and Chongkham-Ang S** (2015) The experience of caregivers living with cancer patients: A systematic review and meta-synthesis. *Journal of Personalized Medicine* **5**(4), 406–439. doi:10.3390/jpm5040406
- Lin F-Y, Rong J-R and Lee TY** (2013) Resilience among caregivers of children with chronic conditions: A concept analysis. *Journal of Multidisciplinary Healthcare* **6**, 323–333. doi:10.2147/JMDH.S46830

- Mazanec SR, Daly BJ, Douglas SL, *et al.* (2011) Work productivity and health of informal caregivers of persons with advanced cancer. *Research in Nursing & Health* **34**(6), 483–495. doi:10.1002/nur.20461
- Molenberghs G, Bijens L and Shaw D (1997) Linear mixed models and missing data. In Verbeke G and Molenberghs G (eds), *Linear Mixed Models in Practice: A SAS-Oriented Approach*. Lecture Notes in Statistics, Vol 126. New York, NY: Springer, 191–274.
- Monod S, Brennan M, Rochat E, *et al.* (2011) Instruments measuring spirituality in clinical research: A systematic review. *Journal of General Internal Medicine* **26**(11), 1345–1357. doi:10.1007/s11606-011-1769-7
- Morris SB, Bass M, Howard E, *et al.* (2020) Stopping rules for computer adaptive testing when item banks have nonuniform information. *International Journal of Testing* **20**(2), 146–168. doi:10.1080/15305058.2019.1635604
- National Academies of Sciences, Engineering, and Medicine (2016) *Families Caring for an Aging America*. Washington, DC: The National Academies Press.
- National Alliance for Caregiving (2016) Cancer caregiving in the US report. [https://www.caregiving.org/wp-content/uploads/2020/05/Cancer-CaregivingReport\\_FINAL\\_June-17-2016.pdf](https://www.caregiving.org/wp-content/uploads/2020/05/Cancer-CaregivingReport_FINAL_June-17-2016.pdf) (accessed 1 October 2020).
- Newberry AG, Choi C-WJ, Donovan HS, *et al.* (2013) Exploring spirituality in family caregivers of patients with primary malignant brain tumors across the disease trajectory. *Oncology Nursing Forum* **40**(3), E119–E125. doi:10.1188/13.ONF.E119-E125
- Nolan S, Saltmarsh P and Leget CJW (2011) Spiritual care in palliative care: Working towards an EAPC task force. *European Journal of Palliative Care* **18**(2), 86–89.
- Northouse LL, Katapodi MC, Schafenacker AM, *et al.* (2012) The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *Seminars in Oncology Nursing* **28**(4), 236–245. doi:10.1016/j.soncn.2012.09.006
- Ochoa CY, Lunsford NB and Smith JL (2020) Impact of informal cancer caregiving across the cancer experience: A systematic literature review of quality of life. *Palliative and Supportive Care* **18**(2), 220–240. doi:10.1017/S1478951519000622
- Park CL (2007) Religiousness/spirituality and health: A meaning systems perspective. *Journal of Behavioral Medicine* **30**(4), 319–328. doi:10.1007/s10865-007-9111-x
- Park CL (2013) The meaning making model: A framework for understanding meaning, spirituality, and stress-related growth in health psychology. *European Health Psychologist* **15**(2), 40–47.
- Park CL and Folkman S (1997) Meaning in the context of stress and coping. *Review of General Psychology* **1**(2), 115–144. doi:10.1037/1089-2680.1.2.115
- Park CL, Pustejovsky JE, Trevino K, *et al.* (2019) Effects of psychosocial interventions on meaning and purpose in adults with cancer: A systematic review and meta-analysis. *Cancer* **125**(14), 2383–2393. doi:10.1002/cncr.32078
- Perez SEV, Maiko S, Burke ES, *et al.* (2022) Spiritual Care Assessment and Intervention (SCAI) for adult outpatients with advanced cancer and caregivers: A pilot trial to assess feasibility, acceptability, and preliminary effects. *American Journal of Hospice and Palliative Medicine* **39**(8), 895–906. doi:10.1177/10499091211042860
- Pioli MF (2010) Global and caregiving mastery as moderators in the caregiving stress process. *Aging and Mental Health* **14**(5), 603–612. doi:10.1080/13607860903586193
- Pitceathly C and Maguire P (2003) The psychological impact of cancer on patients' partners and other key relatives. *European Journal of Cancer* **39**(11), 1517–1524. doi:10.1016/S0959-8049(03)00309-5
- Posluszny DM, Bovbjerg DH, Syrjala KL, *et al.* (2019) Correlates of anxiety and depression symptoms among patients and their family caregivers prior to allogeneic hematopoietic cell transplant for hematological malignancies. *Supportive Care in Cancer* **27**(2), 591–600. doi:10.1007/s00520-018-4346-3
- Puchalski C, Ferrell B, Virani R, *et al.* (2009) Improving the quality of spiritual care as a dimension of palliative care: The report of the Consensus Conference. *Journal of Palliative Medicine* **12**(10), 885–904. doi:10.1089/jpm.2009.0142
- Puchalski CM, Vitillo R, Hull SK, *et al.* (2014) Improving the spiritual dimension of whole person care: Reaching national and international consensus. *Journal of Palliative Medicine* **17**(6), 642–656. doi:10.1089/jpm.2014.9427
- Reed PG (1986) Religiousness among terminally ill and healthy adults. *Research in Nursing & Health* **9**(1), 35–41. doi:10.1002/nur.4770090107
- Reed PG (1987) Spirituality and well-being in terminally ill hospitalized adults. *Research in Nursing & Health* **10**(5), 335–344. doi:10.1002/nur.4770100507
- Reed PG (1992) An emerging paradigm for the investigation of spirituality in nursing. *Research in Nursing & Health* **15**(5), 349–357. doi:10.1002/nur.4770150505
- Reinert KG and Koenig HG (2013) Re-examining definitions of spirituality in nursing research. *Journal of Advanced Nursing* **69**(12), 2622–2634. doi:10.1111/jan.12152
- Rezash V, Reed J, Gedeon B, *et al.* (2020) Who needs what? Perceptions of patients and caregivers in oncology phase 1 trials. *Journal of Patient Experience* **7**(1), 27–33. doi:10.1177/2374373519830743
- Rhee YS, Yun YH, Park S, *et al.* (2008) Depression in family caregivers of cancer patients: The feeling of burden as a predictor of depression. *Journal of Clinical Oncology* **26**(36), 5890–5895. doi:10.1200/JCO.2007.15.3957
- Rivera HR (2009) Depression symptoms in cancer caregivers. *Clinical Journal of Oncology Nursing* **13**(2), 195–202. doi:10.1188/09.CJON.195-202
- Roick J, Danker H, Dietz A, *et al.* (2020) Predictors of changes in quality of life in head and neck cancer patients: A prospective study over a 6-month period. *European Archives of Oto-Rhino-Laryngology* **277**(2), 559–567. doi:10.1007/s00405-019-05695-z
- Ross A, Perez A, Wehrlen L, *et al.* (2020) Factors influencing loneliness in cancer caregivers: A longitudinal study. *Psycho-Oncology* **29**(11), 1794–1801. doi:10.1002/pon.5477
- Rumpold T, Schur S, Amering M, *et al.* (2016) Informal caregivers of advanced-stage cancer patients: Every second is at risk for psychiatric morbidity. *Supportive Care in Cancer* **24**(5), 1975–1982. doi:10.1007/s00520-015-2987-z
- Sato T, Fujisawa D, Arai D, *et al.* (2021) Trends of concerns from diagnosis in patients with advanced lung cancer and their family caregivers: A 2-year longitudinal study. *Palliative Medicine* **35**(5), 943–951. doi:10.1177/02692163211001721
- Schumacher KL, Stewart BJ and Archbold PG (2007) Mutuality and preparedness moderate the effects of caregiving demand on cancer family caregiver outcomes. *Nursing Research* **56**(6), 425–433. doi:10.1097/01.NNR.0000299852.75300.03
- Selman L, Harding R, Gysels M, *et al.* (2011) The measurement of spirituality in palliative care and the content of tools validated cross-culturally: A systematic review. *Journal of Pain and Symptom Management* **41**(4), 728–753. doi:10.1016/j.jpainsymman.2010.06.023
- Sherman DW (2019) A review of the complex role of family caregivers as health team members and second-order patients. *Healthcare (Basel, Switzerland)* **7**(2), 63. doi:10.3390/healthcare7020063
- Sibeoni J, Picard C, Orri M, *et al.* (2018) Patients' quality of life during active cancer treatment: A qualitative study. *J BMC Cancer* **18**, 951. doi:10.1186/s12885-018-4868-6
- Sikorskii A, Victorson D, O'Connor P, *et al.* (2018) PROMIS and legacy measures compared in a supportive care intervention for breast cancer patients and caregivers: Experience from a randomized trial. *Psycho-Oncology* **27**(9), 2265–2273. doi:10.1002/pon.4825
- Sklenarova H, Krümpelmann A, Haun MW, *et al.* (2015) When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer* **121**(9), 1513–1519. doi:10.1002/cncr.29223
- Spatuzzi R, Giulietti MV, Ricciuti M, *et al.* (2017) Quality of life and burden in family caregivers of patients with advanced cancer in active treatment settings and hospice care: A comparative study. *Death Studies* **41**(5), 276–283. doi:10.1080/07481187.2016.1273277
- Sprick PJ, Tata B, Kelly B, *et al.* (2021) Religious/spiritual concerns of patients with brain cancer and their caregivers. *Annals of Palliative Medicine* **10**(1), 964–969. doi:10.21037/apm-20-813
- Steinhauser KE, Fitchett G, Handzo GF, *et al.* (2017) State of the science of spirituality and palliative care research part I: Definitions, measurement, and outcomes. *Journal of Pain and Symptom Management* **54**(3), 428–440. doi:10.1016/j.jpainsymman.2017.07.028

- Stenberg U, Cvancarova M, Ekstedt M, et al.** (2014) Family caregivers of cancer patients: Perceived burden and symptoms during the early phases of cancer treatment. *Social Work in Health Care* **53**(3), 289–309. doi:10.1080/00981389.2013.873518
- Streck BP, Wardell DW, LoBiondo-Wood G, et al.** (2020) Interdependence of physical and psychological morbidity among patients with cancer and family caregivers: Review of the literature. *Psycho-oncology* **29**(6), 974–989. doi:10.1002/pon.5382
- Sun F and Hodge DR** (2012) Latino Alzheimer's disease caregivers and depression: Using the stress coping model to examine the effects of spirituality and religion. *Journal of Applied Gerontology* **33**(3), 291–315. doi:10.1177/0733464812444462
- Thoresen CE and Harris AHS** (2002) Spirituality and health: What's the evidence and what's needed? *Annals of Behavioral Medicine* **24**(1), 3–13. doi:10.1207/S15324796ABM2401\_02
- Trevino KM, Prigerson HG and Maciejewski PK** (2018) Advanced cancer caregiving as a risk for major depressive episodes and generalized anxiety disorder. *Psycho-Oncology* **27**(1), 243–249. doi:10.1002/pon.4441
- Vindrola-Padros C, Brage E and Chambers P** (2018) On the road and away from home: A systematic review of the travel experiences of cancer patients and their families. *Supportive Care in Cancer* **26**(9), 2973–2982. doi:10.1007/s00520-018-4266-2
- Weaver AJ and Flannelly KJ** (2004) The role of religion/spirituality for cancer patients and their caregivers. *Southern Medical Journal* **97**(12), 1210–1214. doi:10.1097/01.SMJ.0000146492.27650.1C
- Wikert J, Treutlein M, Theochari M, et al.** (2021) How does spirituality manifest in family caregivers of terminally ill cancer patients? A qualitative secondary analysis. *Palliative and Supportive Care* **20**(1), 45–54. doi:10.1017/S1478951521000353
- Yoon KH, Moon YS, Lee Y, et al.** (2018) The moderating effect of religiosity on caregiving burden and depressive symptoms in caregivers of patients with dementia. *Aging and Mental Health* **22**(1), 141–147. doi:10.1080/13607863.2016.1232366
- Zarit SH, Todd PA and Zarit JM** (1986) Subjective burden of husbands and wives as caregivers: A longitudinal study. *The Gerontologist* **26**(3), 260–266. doi:10.1093/geront/26.3.260
- Zheng Y, Cotton AC, He L, et al.** (2021) Spirituality-integrated interventions for caregivers of patients with terminal illness: A systematic review of quantitative outcomes. *Journal of Religion and Health* **60**(4), 2939–2959. doi:10.1007/s10943-021-01221-w