

# Exploring Spirituality in Family Caregivers of Patients With Primary Malignant Brain Tumors Across the Disease Trajectory

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**M**ore than 66 million adults in the United States are in need of family care, and 29% of the population consider themselves to be informal caregivers to the chronically ill, disabled, or elderly (National Family Caregivers Association, 2011). In addition, about one in five family caregivers provides more than 40 hours of care per week for a loved one (National Family Caregivers Association, 2011). A number of negative outcomes could result from providing care, including increased depressive symptoms, burden, anxiety, changed sleep patterns, altered immune responses, and poor overall health (Kiecolt-Glaser et al., 2003; Lazarus, 1974; Pinquert & Sörensen, 2004; Schulz & Beach, 1999; Sherwood et al., 2008; Vitaliano et al., 2002; Vitaliano, Zhang, & Scanlan, 2003).

Outside of the caregiving literature, a strong perception of spirituality has been associated with lower rates of depressive symptoms, less distress, and better quality of life in individuals recently diagnosed with a life-threatening disease (Chang, Noonan & Tennstedt, 1998). Positive associations have been identified between religion or spirituality and mental health (Chang et al., 1998; Levin, 2010; Poloma & Pendleton, 1989), particularly for patients with terminal illnesses such as AIDS and advanced cancer (Kendall, 1994; Vallurupalli et al., 2012). However, less is known about how spirituality affects family caregivers, particularly as the needs and prognosis of the care recipient and the responsibilities of the caregiver change along the course of the disease trajectory.

Because of the established association between the caregiver role and experiencing negative outcomes (Rhee et al., 2008), potential sources of support for caregivers must be explored. If associations between spirituality and positive outcomes extend to family caregivers, clini-

**Purpose/Objectives:** To determine whether the perceived level of spirituality in family caregivers of patients with primary malignant brain tumors (PMBTs) changes across the disease trajectory.

**Design:** Ongoing descriptive, longitudinal study.

**Setting:** Southwestern Pennsylvania.

**Sample:** 50 family caregivers of patients with PMBT.

**Methods:** Caregivers and care recipients were recruited at time of diagnosis. Participants were interviewed at two subsequent time points, four and eight months following diagnosis.

**Main Research Variables:** Care recipients' symptoms, neuropsychologic status, and physical function, as well as caregiver social support.

**Findings:** Results showed no significant difference in spirituality scores reported at baseline and eight months ( $p = 0.8$ ), suggesting that spirituality may be a stable trait across the disease trajectory.

**Conclusions:** Spirituality remains relatively stable along the course of the disease trajectory. Reports of caregiver depressive symptoms and anxiety were lower when paired with higher reports of spirituality.

**Implications for Nursing:** Clinicians can better identify caregivers at risk for negative outcomes by identifying those who report lower levels of spirituality. Future interventions should focus on the development and implementation of interventions that provide protective buffers such as increased social support.

**Knowledge Translation:** Spirituality is a relatively stable trait. High levels of spirituality can serve as a protective buffer from negative mental health outcomes. Caregivers with low levels of spirituality may be at risk for greater levels of burden, anxiety, and stress.

cians could use this information to screen caregivers at risk for distress and implement interventions that build on or strengthen existing spirituality. The purpose of the current analysis was to determine whether family

caregivers of people with primary malignant brain tumors (PMBTs) experienced changes in their perceived level of spirituality along the course of the disease trajectory as the characteristics of the care recipient potentially change, and to examine the impact of spirituality on caregivers' depressive symptoms and anxiety eight months after patients' diagnoses.

## Background

Spirituality can provide meaning and purpose to challenging situations, and has been an important concept in the literature (Bingham & Habermann, 2006; Pesut, 2008). In the nursing literature, spirituality is sometimes vague or abstract in definition; however, it encompasses a multidimensional connectedness and includes interpersonal, intrapersonal, and transpersonal connectedness (Kim, Reed, Hayward, Kang, & Koenig, 2011). Interpersonal connectedness refers to relationships with other individuals, nature, and surroundings; intrapersonal connectedness relates to a personal relationship with oneself as well as focusing on centeredness and inner strength; and transpersonal connectedness relates to a sense of oneness or relation with God or a higher power (Kim et al., 2011; Reed, 1992).

Stress related to caregiving also has been well represented in the literature and often is associated with caregivers performing physically, socially, emotionally, or financially demanding tasks because of the added strain of caring for a loved one suffering from an illness and from lack of social support and guidance from healthcare professionals (Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004; Schubart, Kinzie, & Farace, 2008). Caregiving stress relates to burden and poor mental functioning in caregivers of patients who have cancer with brain tumors (Colgrove, Kim, & Thompson, 2007; Schmer, Ward-Smith, & Salacz, 2008; Tamayo, Broxon, Munsell, & Cohen, 2010). Caregivers of patients with PMBTs often are faced with the abrupt onset of symptoms, diagnosis, and poor prognosis. In addition, they may face the need to remain in the caregiving role for an extended period of time. The average survival rate for glioblastoma, the most aggressive malignant brain tumor, is 12 months with treatment. Fewer than 24% of patients with less-aggressive grades III or IV malignant tumors survive two years postdiagnosis, and fewer than 10% survive after five years (Schmer et al., 2008). Those discouraging statistics paired with the physical and emotional burden of caregiving may lead to feelings of hopelessness and distress (Osse, Vernooij-Dassen, Schadé, & Grol, 2006).

Spiritual well-being is an important factor that can influence caregiver burden or physical, emotional, financial, and social hardship, as well as psychological health. Research indicated that an inverse relationship

between spiritual well-being and burden exists where caregivers who reported higher levels of spiritual well-being tended to have lower burden scores (Spurlock, 2005). Caregivers who find spiritual meaning in the care situation may develop a buffer that sustains their psychological well-being, which may protect them from the aversive affects of caregiving stress (Colgrove et al., 2007; Herrera, Lee, Nanyonjo, Laufman, & Torres-Vigil, 2009).

A relationship also has been identified between spiritual coping and caregiving distress. Caregivers who used their spiritual beliefs as a coping mechanism reported a higher quality relationship with the care recipient and lower levels of depressive symptoms and anxiety compared to those who did not (Chang et al., 1998). Hebert, Dang, and Schulz (2007) explored the relationship between spirituality and mental health in family caregivers and determined that spiritual rituals and practices were associated with lower depression and better overall mental health.

Studies have focused on the presence of burden and distress in family caregivers and highlighted the positive impact of spiritual well-being in that population. Although those are important additions to the literature, specific variables that may contribute to those factors have not been well established, particularly in the neuro-oncology caregiving population. Using the Pittsburgh Mind Body Center Model as a guide, the current analysis evaluated caregiver health over time with particular attention given to care recipients' disease characteristics from diagnosis throughout treatment, which may trigger psycho-behavioral and subsequent biologic responses in caregivers, which lead to changes in overall physical health. Spirituality may impact caregivers' psycho-behavioral health (Sherwood et al., 2008).

## Methods

Data were collected from participants previously enrolled in an ongoing descriptive, longitudinal study (Sherwood, n.d.) that examined the psycho-behavioral responses, biologic responses, and overall physical health of family members of people with PMBTs from the time of diagnosis to eight months following the diagnosis. Caregivers and care recipients were recruited through an urban outpatient neuro-surgery or neuro-oncology clinic within one month of the care recipient's diagnosis and completed questionnaires at diagnosis and eight months. Eight-month follow-up data were used for analysis because tumor status (i.e., recurrence) and response to treatment usually can be determined by that point in the disease trajectory.

Caregivers and care recipients provided individual consent. Attrition occurred when the care recipient died or communicated to the research team that they did not wish to continue participation in the project. Caregivers

were considered eligible if they were nonprofessional (i.e., not paid), aged 21 years or older, had regular and reliable access to a telephone, could read and speak English, and were not a primary caregiver for anyone else (excluding children younger than age 21 years). Care recipients were eligible if they were diagnosed with PMBTs no more than one month prior (verified by surgical pathology) and aged 21 years or older. Institutional review board approval was obtained prior to participants' consent. At the time of analysis, 129 pairs were approached by research staff and 76 consented to participate. Fifty pairs (N = 100) completed data points at baseline and eight months and were included in the current study.

## Instruments: Caregivers

Research staff conducted face-to-face or telephone interviews with the caregivers, each lasting 60–90 minutes. The interviews took place either in the neurosurgery clinic or the caregivers and recipients' homes. The two members of the research team interviewed the caregiver and care recipient separately and collected sociodemographic information regarding age, gender, level of education, relationship, ethnicity, and income. A number of instruments were included in the interviews to provide information on caregiver psychological functioning.

**Depression:** A nine-item shortened version of the **Center for Epidemiologic Studies–Depression Scale (CES-D)** was used to measure caregivers' depressive symptoms. Participants used a four-point Likert-type scale to indicate how often they experienced symptoms such as difficulty concentrating, feeling fearful, and feeling lonely. Individual items were summed to produce an overall score, and higher scores indicated higher levels of depressive symptoms. Validity for the CES-D was established in caregivers and healthy adults (Cronbach alpha = 0.87; nine items) (Andresen, Malmgren, Carter, & Patrick, 1994; Logsdon & Teri, 1995).

**Anxiety:** Anxiety was measured using a shortened version of the anxiety subscale of the **Profile of Mood States (POMS)** scale (Usala & Hertzog, 1989). Participants rated how often they experienced various symptoms using a five-point Likert-type scale. Individual items were summed to produce a total score, and higher scores indicated greater anxiety. Validity for the POMS was established using several other anxiety measures such as the **Symptom Checklist-90 Revised** and the **Bradburn Positive and Negative Affect Scales** (Cronbach alpha = 0.9; three items) (Baker, Denniston, Zabora, Polland, & Dudle, 2002; Barker-Collo, 2003).

**Neuroticism:** Neuroticism was measured using Goldberg's (1992) modified adjective scale. Participants indicated how well certain adjectives described them using a five-point Likert-type scale. A neuroticism score was generated by summing individual items, and higher

scores indicated stronger traits. Goldberg's (1992) adjective scale is a valid measure of personality type when compared to the NEO Personality Inventory and clinical examination (Cronbach alpha = 0.77) (Egger, Delsing, & DeMey, 2003; Saucier, 1994).

**Social support:** Social support was measured using the **Interpersonal Evaluation List (ISEL)**. Participants rated the availability of three types of social support: tangible, appraisal, and belonging. Tangible social support refers to perceived availability of aid in the material form; appraisal is defined as the perceived availability of another person with whom to discuss problems; and belonging is the perceived availability of people with whom caregivers can do things (e.g., recreational activities) (Brookings & Bolton, 1988). Individual items were summed to produce a score for each subscale, and subscale scores were summed to produce an overall support score. Higher scores reflected more social support. Validity for the ISEL was established using the **Inventory of Socially Supportive Behaviors**, number of perceived close friends, and the **Partner Adjustment Scale** (Cronbach alpha = 0.87, 10 items) (Brookings & Bolton, 1988; Cohen, 1991; Cohen, Mermelstein, Kamarck, & Hoberman, 1985; Schonfeld, 1991).

**Spirituality:** Spirituality was assessed with the **Functional Assessment of Chronic Illness Therapy Spiritual Well-Being Scale (FACIT-sp)**. The 12-item measure has a Likert-type rating scale score from 0–4, indicating the degree to which one agrees with statements in each item. The measure contains two subscales: one measures a sense of meaning and peace and the other assesses the role of faith as it relates to illness. A total score was generated, and higher scores indicated higher levels of spirituality (Cronbach alpha = 0.9) (Cella et al., 1993). Reliability and validity for the total scale and the two subscales have been established (Cronbach alpha = 0.81, –0.88) (Peterman et al., 2002).

## Instruments: Care Recipients

Care recipients participated in interviews that ranged from 30–60 minutes and took place at the home of the caregiver and care recipient or in the neurosurgery clinic. Interviews were conducted by research assistants who read questions to the care recipient and recorded responses. Sociodemographic information such as age, gender, employment status, and income was collected in addition to clinical information on tumor type and treatment.

**Neurologic:** The **Neurobehavioral Cognitive Status Examination (NCSE)** assessed patients' neurologic status in multiple cognitive domains, including level of consciousness, attention, language, constructional ability, memory, calculations, and reasoning (Kiernan, Mueller, Langston, & Van Dyke, 1987). Participants answered questions and performed tasks to indicate



**Table 1. Caregiver Sociodemographic and Clinical Characteristics (N = 50)**

Characteristic	n
<b>Gender</b>	
Female	39
Male	11
<b>Relationship to care recipient</b>	
Spouse or significant other	38
Parent	7
Daughter or son	3
Sister or brother	1
Friend or companion	1
<b>Care recipient tumor type</b>	
Glioblastoma	25
Astrocytoma I–III	6
Other	19
<b>Religious preference</b>	
Protestant	18
Catholic	17
Jewish	2
Other	6
Not applicable	7

ability in the different domains. Scores were generated for each domain via algorithm (average ability = 0, mild impairment = 1, moderate impairment = 2, and severe impairment = 3), and an overall score was calculated by summing the scores for each domain. Higher scores indicated higher levels of neurologic dysfunction.

**Symptom severity:** The MD Anderson Symptom Inventory–Brain Tumor Model (MDASI-BT) determined the presence and severity of symptoms related to the disease or treatment of the patient. MDASI-BT's 22 items include symptoms most frequently and severely experienced in patients with brain tumors in addition to six 10-point rating scales for patients to indicate the extent that those symptoms interfere with ability to function (Armstrong, 2006). A component score for the symptom severity scale was obtained by summing the rating averages for each item together. The symptom interference score was calculated by summing the mean scores of each of the six scales (Cronbach alpha = 0.92) (Cleeland et al., 2000).

### Instruments: Associative

To explore associations with depressive symptoms and anxiety, univariate analyses using Spearman's correlations (Spearman, 2010). were performed on caregivers' characteristics (age, gender, relationship to care recipient) and care recipients' characteristics (tumor type, NCSE domain scores, and symptom severity) at diagnosis. Characteristics significantly associated with outcomes at  $p < 0.1$  were evaluated further in multiple linear regression models.

Multiple linear regressions were performed on caregivers' depressive symptoms and anxiety predicted

by spirituality scores at eight months while controlling for caregivers' and care recipients' characteristics at diagnosis. Regression models were selected using block testing. Block 1 consisted of fixed factors (age, gender, relationship to care recipient, and tumor type) in the model. Block 2 consisted of exploratory factors that were correlated significantly in the univariate analysis (care recipients' NCSE domain scores and symptom severity).

## Results

The majority of caregivers were female spouses of the patient, Protestant or Catholic, aged 51 years (SD = 11.3, range = 24–72), and completed an average of 14 years of formal education (SD = 1.9, range = 12–19) (see Table 1). The most prevalent tumor type was a glioblastoma. The Friedman test analyzed whether spirituality scores changed from diagnosis to eight months (Friedman, 1937). Results showed no significant difference in spirituality scores reported at baseline and eight months ( $p = 0.8$ ).

### Depressive Symptoms at Eight Months

Table 2 shows the final regression model for caregiver depression. After adjusting for age, gender, relationship to care recipients, and care recipients' tumor type, caregivers' level of spirituality significantly predicted their levels of depressive symptoms at eight months postdiagnosis ( $F[6,65] = 12.47$ ,  $p < 0.01$ ,  $R^2 = 0.54$ ). Caregivers with higher levels of spirituality reported fewer depressive symptoms than caregivers with lower levels of spirituality ( $\beta = -0.41$ ,  $p < 0.01$ ). In addition, care recipients diagnosed with

**Table 2. Regression Model Predicting Caregiver Depressive Symptoms at Eight Months Following Diagnosis<sup>a</sup>**

Caregiver Characteristic	$\beta$	SE	p
<b>Spirituality at eight months</b>	−0.41	0.06	< 0.01
<b>Age (years)</b>	−0.04	0.04	0.38
<b>Gender (versus male)</b>			
Female	0.65	1.19	0.59
<b>Relationship to care recipient (versus nonspouse)</b>			
Spouse or significant other	0.59	1.18	0.62
<b>Care recipient tumor type (versus glioblastoma)</b>			
Astrocytoma I–III	2.55	1.46	0.08
Other <sup>b</sup>	−2.95	1.15	0.01

<sup>a</sup>  $F[6,65] = 12.47$ ;  $R^2 = 0.54$ ;  $p < 0.001$

<sup>b</sup> Oligos, infiltrating gliomas, large B-cell lymphomas, malignant gliomas, and subependymomas

SE—standard error

a glioblastoma reported significantly higher levels of depressive symptoms than those with other tumor types ( $\beta = -2.95$ ,  $p = 0.01$ ). Care recipients who reported higher symptom severity ( $\beta = 0.032$ ,  $p = 0.18$ ) and poorer functioning (comprehension  $\beta = -1.1$ ,  $p = 0.18$ ; reasoning  $\beta = -0.053$ ,  $p = 0.9$ ) were associated with caregivers who reported higher depressive symptoms; however, those results were not statistically significant.

### Anxiety at Eight Months

Spearman's correlations (Spearman, 2010) identified univariate associations ( $p < 0.1$ ) between caregivers' anxiety and care recipients' symptom severity ( $\rho = 0.23$ ,  $p = 0.08$ ) and NCSE scores in language comprehension ( $\rho = -0.24$ ,  $p = 0.07$ ), digit repetition ( $\rho = -0.22$ ,  $p = 0.09$ ) and judgment ( $\rho = -0.26$ ,  $p = 0.04$ ). Care recipients with higher symptom severity and poorer language comprehension, attention, and judgment were associated with higher anxiety in their caregivers. However, those factors did not significantly add to the regression model and were excluded ( $R^2 = 0.09$ ,  $p = 0.12$ ). The final regression model for caregiver anxiety is listed in Table 3. Spirituality significantly predicted anxiety at eight months after adjusting for other factors ( $F[6,64] = 3.86$ ,  $p < 0.01$ ,  $R^2 = 0.27$ ). Caregivers who scored higher on spirituality reported significantly less anxiety ( $\beta = -0.13$ ,  $p < 0.01$ ). Female caregivers also reported higher anxiety compared to their male counterparts ( $\beta = 1.53$ ,  $p = 0.02$ ).

### Discussion

Results from the current analysis indicated that spirituality remains relatively stable along the course of the disease trajectory. That finding is meaningful when accounting for the stressors and changes that occur during the eight months, such as chemotherapy, radiation, and the potential recurrence of tumors and the care recipient's death. Although less is known about changes in spirituality across time, research reported that high levels of spirituality moderate stress and mental health in caregivers, and may provide a buffer from the adverse effects that result from providing care (Colgrove et al., 2007; Spurlock, 2005). The current data support that hypothesis, as reports of depressive symptoms and anxiety were lower when paired with higher reports of spirituality.

The role of spirituality was an important mediator in the relationship between care demands and caregiver outcomes. Multiple variables linked to poor caregiver outcomes (e.g., care recipients' symptoms, neuropsychologic status, physical function, caregiver social support) often changed over the course of the current participants' care trajectory. In the case of poor caregiver outcomes, identifying a buffer that would remain stable over the care trajectory is an important variable to target

**Table 3. Regression Model Predicting Caregiver Anxiety at Eight Months Following Diagnosis<sup>a</sup>**

Caregiver Characteristic	$\beta$	SE	p
Spirituality at eight months	-0.13	0.03	< 0.001
Age (years)	-0.02	0.02	0.39
Gender (versus male)			
Female	1.53	0.65	0.02
Relationship to care recipient (versus nonspouse)			
Spouse or significant other	1.081	0.65	0.1
Care recipient tumor type (versus glioblastoma)			
Astrocytoma I-III	-0.07	0.79	0.93
Other <sup>b</sup>	0.14	0.63	0.83

<sup>a</sup>  $F(6,64) = 3.86$ ;  $R^2 = 26.6$ ;  $p = 0.002$

<sup>b</sup> Oligos, infiltrating gliomas, large B-cell lymphomas, malignant gliomas, and subependymomas

SE—standard error

when identifying caregivers at risk for poor outcomes and implementing interventions to support caregiver spirituality.

Although data are encouraging for caregivers who report higher levels of spirituality, researchers should take note of caregivers who report low levels of spirituality. As the current results indicate, spirituality appeared stable across time despite the stressors, life changes, and role changes of the caregiver. Caregivers who report low levels of spirituality may be at risk for high levels of burden, anxiety, and stress across the trajectory of their loved one's illness. The emotional health of those caregivers may be jeopardized, which could compromise their ability to provide quality care, resulting in poor caregiver health.

The current results indicate that eight months after care recipients' diagnoses, caregivers reported higher levels of depressive symptoms if the care recipients demonstrated higher symptom severity and poorer functioning in language and reasoning. In a study conducted by Rhee et al. (2008), family caregivers of patients with cancer displayed higher levels of depression when the patient they were caring for scored poorly on the Eastern Cooperative Oncology Group performance status, a scale used to assess the extent to which the patient could perform normal activities. Rhee et al.'s data suggested that quality of life and family impact may have strong influences on caregivers' depressive symptoms. In the current study, higher symptom severity and functioning impacted family dynamics and the quality of life for all family members, which supports Rhee et al.'s findings. In addition, in the current study, caregivers of spouses reported higher levels of depressive symptoms compared to caregivers caring for nonspouses. That finding also

is consistent with the work of Rhee et al. (2008), who reported that spousal caregivers presented higher scores in depressive symptoms.

Care recipients with higher symptom severity and poor language comprehension, attention, and judgment scores were associated with higher levels of anxiety in spousal as well as nonspousal caregivers. Although caregiving stress was associated with poor mental functioning in care recipients, it occurred far less in caregivers who reported higher levels of spirituality, emphasizing the buffering effect of spirituality. The current results are consistent with those of Spurlock (2005), who found that family caregivers of patients with Alzheimer reported less caregiving stress and burden when their spiritual well-being scores were higher. Similarly, female caregivers of patients with a variety of cancer diagnoses were found to have higher levels of psychological stress related to caregiving when they reported lower levels of spirituality (Kim, Wellisch, Spillers, & Crammer, 2007), which may indicate that caregivers use spirituality as a coping strategy to combat the stress of providing care to a loved one.

## Limitations

Several limitations to the current study should be noted. The religious affiliations of caregivers included in the current study were primarily Catholic and Protestant, and, therefore, have limited generalizability across members of other religions. In addition, participants were recruited in urban, suburban, and rural settings across Western Pennsylvania and comprised a fairly homogenous sample in terms of sociodemographic characteristics (e.g., race, income, education). Most caregivers were middle-aged females and a large majority of care recipients were their male spouses. Although the current analysis may have appeared to view caregivers of patients with brain tumors through a narrow lens, the sample is reflective of the way in which the disease presents itself in the general population. Malignant brain tumors are most common in Caucasian, middle-aged males, and the majority of family caregivers are spousal females of the same race.

## Implications for Research

Future work should focus on replicating and expanding results by studying caregivers for longer periods of time and across different demographic areas and populations. In addition, the analysis focused only on caregivers of care recipients who were still living eight months postdiagnosis. Spirituality levels of bereaved caregivers should be compared to the levels of caregivers whose loved ones are still living to determine if significant changes occur when the caregiver's role and way of life changes dramatically. In addition, the measure assessed level of spirituality rather than religiosity. Therefore, future research should target a greater understanding of other concepts (e.g., amount of prayer per day, attendance at religious services) to develop the most appropriate interventions.

## Implications for Clinicians

Understanding the established role of spirituality during challenging and traumatic situations is relevant to the current findings (Bingham & Habermann, 2006; Spurlock, 2005). Spirituality as a coping mechanism is not universally used or desired by caregivers. Researchers and clinicians should seek to better understand other forms of interventions that also provide the protective buffer provided by high levels of spirituality, such as psychosocial support groups, mediation, and pastoral care.

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