

# 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