Identifying Family Members Who Are Likely to Perceive Benefits From Providing Care to a Person With a Primary Malignant Brain Tumor

Alyssa Newberry, MEd, Jean Kuo, MS, Heidi Donovan, PhD, RN, Barbara Given, PhD, RN, FAAN, Charles W. Given, PhD, Richard Schulz, PhD, and Paula Sherwood, PhD, RN, CNRN

The body of literature on family caregiving has begun to capture and document many aspects of the overall caregiving experience. The majority of research has focused on negative reactions (e.g., burden, depressive symptoms) that result when family members assume the role of caregiver and are forced to make sacrifices and major life changes to adapt to their new responsibilities. Recent studies suggest that benefits and rewards also can be associated with providing care (e.g., personal growth, discovering a sense of purpose) that coexist with the less-favorable reactions (Boerner, Schulz, & Horowitz, 2004; Kramer, 1997; Tarlow et al., 2004).

Although research has shown that these positive aspects of caring (PAC) can be present within the caregiving experience, studies have yet to identify family caregivers who are and are not likely to perceive benefits and rewards from providing care. To help family caregivers maintain their emotional health and potentially improve the quality of patient care delivered in the home, identifying how caregivers’ perception of the benefits and rewards of providing care change over time as a function of patient and caregiver characteristics is vital.

The purpose of the current study was to identify changes in positive aspects of care (PAC) from the time of diagnosis to four months following the diagnosis in family caregivers of care recipients with primary malignant brain tumors.

**Purpose/Objectives:** To identify changes in positive aspects of care (PAC) from the time of diagnosis to four months following the diagnosis in family caregivers of care recipients with primary malignant brain tumors.

**Design:** Longitudinal.

**Setting:** Dyads were recruited from neurosurgery clinics in Pittsburgh, PA, at the time of care recipients’ diagnosis with a primary malignant brain tumor. A second data collection took place four months following the diagnosis.

**Sample:** 89 caregiver and care recipient dyads.

**Methods:** Paired t tests were used to examine change in PAC, univariate analyses were used to determine predictors of PAC at four months, Mann-Whitney U tests and t tests were used to examine associations between categorical predictor variables and PAC at four months, and univariate linear regressions were used to examine associations between continuous predictors and PAC at four months.

**Main Research Variables:** The impact of sociodemographic factors, caregiver-perceived social support, mastery, neuroticism, and marital satisfaction on PAC.

**Findings:** Caregivers’ PAC scores during the first four months following diagnosis appeared to remain stable over time. Significant differences were found between the care recipient reasoning domain group at diagnosis and PAC score. Care recipients who scored below average were associated with caregivers with higher PAC scores. Caregiver PAC at four months following diagnosis was significantly predicted by care recipient reasoning and caregiver social support.

**Conclusions:** PAC scores appear to remain stable over time, although levels of PAC may be related to care recipients’ level of functioning. Future research should focus on the development of interventions for caregivers who report low levels of PAC at the time of diagnosis in an attempt to help these individuals identify PAC in their caregiving situation.

**Implications for Nursing:** Findings have clinical and research implications. Clinicians may be able to better identify caregivers who are at risk for negative outcomes by understanding the risks faced by caregivers of patients with milder symptoms in addition to those caring for more profoundly affected care recipients.