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# Changes in Caregiver Perceptions Over Time in Response to Providing Care for a Loved One With a Primary Malignant Brain Tumor

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**P** rimary malignant brain tumors (PMBTs) have a unique treatment and disease trajectory as compared to other cancers. Having a brain tumor not only subjects the patients to issues inherent in a cancer diagnosis (e.g., side effects from chemotherapy and radiation) but often causes significant neurologic deficits that interfere with daily life and function. Neurologic deficits can include physical deficits as well as cognitive decline in memory, attention, language and communication, executive function, reasoning, judgment, and mental flexibility (Sherwood et al., 2006).

The presence of these complications leads to many difficulties for family caregivers of those with PMBT. For example, patients often are forced to quit their jobs upon diagnosis, which requires the family caregivers to maintain employment to ensure medical benefits. Neurologic dysfunction, such as memory loss or inappropriate behavior, may limit the number of social activities the dyad may engage in and typically increases household responsibilities, such as managing finances, for the caregiver. To provide the best possible care to the patient, caregivers' needs and concerns must be acknowledged to minimize the stress and burden they experience. Research has shown that providing care for patients with dementia produces negative psychological and behavioral (psychobehavioral) responses, such as depressive symptoms, caregiver burden, and altered sleep patterns (Brummett et al., 2006). However, the majority of the studies have been cross-sectional and do not address how and when caregiver distress emerges in the care situation. In addition, almost no attention has been paid to caregivers of patients with PMBT. The purpose of the current study was to examine the transition from family member to caregiver and to explore changes in caregivers' perceptions of that transition during the first four months following diagnosis. These data are vital for implementing the most

**Purpose/Objectives:** To examine how family members of patients with a primary malignant brain tumor transition into the caregiver role and how their perceptions of this transition change over time.

**Research Approach:** Descriptive, qualitative.

**Setting:** Neurosurgery and neuro-oncology clinics of a regional medical center.

**Participants:** 10 family caregivers of patients with a primary malignant brain tumor.

**Methodologic Approach:** A series of 11 open-ended questions addressing various aspects of the care situation were administered to each caregiver. The same questions were asked at baseline (within one month of the patient's diagnosis) and four months later. Content analysis was performed to identify themes among interviews.

**Main Research Variables:** Patient changes, caregiver adjustments, and accessing support.

**Findings:** Caregivers described difficulties stemming from the patient's tumor-related dysfunction and changes in their familial, occupational, and social roles. Support from family and friends was vital to caregivers' emotional health, but shock and fear were evident in all interviews. Becoming subsumed in the care situation was described as *enmeshment*. Caregivers reported difficulty in communicating with healthcare providers. When looking at change over time, three major themes emerged: Patient Changes: The New Normal; Caregiver Adjustments; and Accessing Support.

**Conclusions:** Caregivers require support in handling neurologic and physical sequelae, transitioning into new roles, and avoiding becoming enmeshed in the care situation.

**Interpretation:** This study underlines the importance of continuing research in this area to provide the necessary interventions that will assist caregivers and provide support throughout their loved one's disease trajectory.

efficient and effective interventions to improve caregiver health by providing the necessary support during the transition of becoming a family caregiver.