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