

# A New Reality: Long-Term Survivorship With a Malignant Brain Tumor

Mary Pat Lovely, PhD, RN, Christina Stewart-Amidei, RN, PhD, APN-CNS, CNRN, CCRN, FAAN, Margaretta Page, RN, MS, Kathleen Mogensen, RN, MSN, APN-C, Jean Arzbaeher, RN, MS, APN-CNS, CNRN, Kathleen Lupica, RN, MSN, CNP, and Mary Ellen Maher, RN, MSN, CNP

An estimated 25,000 new cases of primary malignant brain tumors (PMBTs) are diagnosed each year in the United States (Central Brain Tumor Registry of the United States [CBTRUS], 2012). Contemporary treatment includes surgical debulking where possible, with concomitant radiation and chemotherapy (Mirimanoff et al., 2006). Even with aggressive multimodality treatment, median survival time for people with a PMBT is about 17 months, with a two-year survival rate at 43% (Mirimanoff et al., 2006). Recent advances in the diagnosis and treatment of PMBTs have improved mortality for those affected, and more people with PMBTs are living for longer periods of time (Steinbach et al., 2006). Survivors are challenged by not only treatment-related morbidities but also by consequences of the disease itself (Steinbach et al., 2006). Unlike many other cancers, unique disease-related deficits may occur because of brain involvement, leaving many survivors to suffer from persistent neurologic and cognitive deficits that interfere with their ability to resume previous activities (Steinbach et al., 2006).

Brain tumor survivors report physical problems such as fatigue, weakness, pain, and neurologic deficits. Studies have shown decreased quality of life (QOL) related to the symptom cluster of depression, fatigue, sleep disturbances, and cognitive impairment (Fox, Lyon, & Farace, 2007; Lovely, Miaskowski, & Dodd, 1999). Cognitive sequelae, including poor short-term memory and difficulties with higher executive functions, are of particular concern to survivors with brain tumors (Giovagnoli, Silvani, Colombo, & Boiardi, 2005). Steinbach et al. (2006) surveyed PMBT survivors (N = 10) who were more than five years from diagnosis and found that neuropsychological status was impaired in at least one area in all patients, with attention deficits being the most prominent sequelae after PMBT treatment. Those survivors reported reductions in multiple aspects of QOL using the European Organisation for Research and Treatment

**Purpose/Objectives:** To explore the survivor experience of adults who have been diagnosed three years or longer with a primary malignant brain tumor (PMBT).

**Research Approach:** Qualitative using a biographical narrative approach.

**Setting:** Six sites across the United States.

**Participants:** Survivors of PMBTs (N = 35) and their family caregivers (N = 35).

**Methodologic Approach:** Using a semistructured interview guide, survivors and caregivers were interviewed individually about their lives before and since the PMBT diagnosis. Thematic analysis was performed to identify themes.

**Findings:** Stability in survivor lives disintegrated as a result of the changes experienced related to the tumor and its treatment. Those changes were profound and ultimately contributed to multiple losses in key areas of their lives. Over time, living with the diagnosis and its consequences required survivors and their caregivers to adapt to the new reality of their lives. Through the process of becoming a survivor, individuals were able to take back control of their lives. Adaptation required survivors to use internal and external resources as ways of coping with their new reality.

**Conclusions:** People with PMBTs require support as they adapt to losses and changes that impact their lives. Assessment of specific changes that impact survivors' lives may be useful in guiding type of support given. Symptom management and mobilization of internal and external resources may lessen the life-changing impact.

**Interpretation:** Nurses should capture symptom meaning during assessments and expand assessments to include social support systems. Instituting measures that facilitate survivor independence may lessen the impact of disability. The significance of symptom worsening over time requires additional research.

**Knowledge Translation:** Restoring self-worth and taking control of their lives are critical concerns for survivors of PMBTs.

of Cancer QOL Questionnaire–Core 30 role functioning scale, which assesses ability to work, perform activities of daily living, and participate in leisure activities.