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