

# The Bereavement Experience for Partners of Patients With Central Nervous System Tumors

Meagan S. Whisenant, PhD, APRN, Stacey Crane, PhD, RN, CPON®, Mackenzie Stewart, BSN, and Kathrin Milbury, PhD

**PURPOSE:** To describe the experience of caregivers who have lost a partner to a central nervous system (CNS) tumor.

**PARTICIPANTS & SETTING:** 8 bereaved partners of patients with CNS tumors enrolled in a dyadic, behavioral randomized controlled trial at a comprehensive cancer center in the southern United States.

**METHODOLOGIC APPROACH:** Participants took part in a semistructured qualitative interview to describe the experience of their partner's death. Descriptive exploratory analysis was used to identify themes emerging from the interviews.

**FINDINGS:** Themes identified from bereaved participants' experiences were related to caring for their partner, separating from their partner on patient death, and continuing without their partner following patient death.

**IMPLICATIONS FOR NURSING:** Bereaved partners of patients with CNS tumors described how difficult it was to experience the patient's health decline and feeling unprepared for the patient's death, regardless of advance notice. Interventions targeting caregiver distress to improve their experience prior to and following the patient's death are needed.

**KEYWORDS** cancer; central nervous system tumor; bereavement; caregivers; qualitative methods

**ONF, 49(2),151-157.**

**DOI** 10.1188/22.ONF.151-157

Patients with central nervous system (CNS) tumors experience a unique range of disease- and treatment-related symptoms, as well as an often rapid decline in physical and mental functioning (Maqbool et al., 2016; Piil et al., 2019; Reblin et al., 2017). Patients with CNS tumors experience cognitive declines, neurological and motor deficits, as well as personality changes due to the disease process and cancer treatment, while also experiencing uncertainty related to the disease course and a general poor prognosis (Piil et al., 2019). Caregivers of patients with CNS tumors manage both oncologic and neurologic patient concerns because patients often experience problems with memory, cognitive processing, visual searching, planning and foresight, and attention, along with physical dysfunction related to tumor location and treatment (Piil et al., 2019). Because of the unique presentation of CNS tumors, caregivers of patients with CNS tumors provide patient support and care, which may include coordinating care, monitoring symptoms, administering medications, managing finances, advocating for the patient, and performing physical care tasks without having received formal training (Piil et al., 2019; Sherwood et al., 2006). In the CNS tumor setting, while serving as the patient's primary caretaker and advocate, caregivers are faced with their own personal challenges associated with the emotional burden of seeing their loved one suffering and anticipating their rapid, further decline and eventual death. Some of these burdens also include the loss of social support and shifts in the relationship, from mutually supportive partners to caregiver and patient (Piil et al., 2019). As the need for caregiving increases with decline of the patient's condition, caregivers increasingly lose social support, forgoing social activities and friendships and often taking leave or retiring from employment to take care of the patient (Wadhwa et al., 2011). With a rapid progression of disease, patients with