

# Maternal Caregiving Demands for Adolescent and Young Adult Survivors of Pediatric Brain Tumors

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**W**ith advances in multimodal therapy, including surgery, chemotherapy, radiation, and supportive care, the five-year survival rate for the 4,300 children who will be diagnosed with a brain tumor in 2015 has improved to 75% (National Cancer Institute, 2013). Therefore, an increasing number of survivors of pediatric brain tumors are living into adolescence and young adulthood while dealing with late effects of treatment, such as cognitive deficits, hearing impairment, visual disturbances, endocrine dysfunction, neurologic deficits, and changes in physical appearance. They may require care long after completing treatment and are less likely than survivors of other childhood cancers to become independent adults (Oeffinger et al., 2006). The demands of caring for these survivors are important to understand because of the implications for their ongoing care, as well as for parental psychosocial and physical health (Klassen et al., 2011). Although the demands of caring for children with chronic conditions (Sullivan-Bolyai, Sadler, Knafl, & Gilliss, 2003; Sullivan-Bolyai, Knafl, Sadler, & Gilliss, 2004), children receiving cancer treatment (Klassen et al., 2011; Wells et al., 2002), and older adults (Northouse, Katapodi, Song, Zhang, & Mood, 2010) have been identified, they have not been determined for the adolescent and young adult (AYA) population.

Mothers typically are the nonprofessional caregivers providing day-to-day care to children who survived pediatric brain tumors (Deatruck, Mullaney, & Mooney-Doyle, 2009; Forinder & Norberg, 2010). The current study takes the first steps in identifying primary caregiver demands directly related to AYA survivors. It seeks to answer the question, "What are the daily caregiving demands experienced by mothers of AYA survivors of pediatric brain tumors who live with their families?" The long-term goal is to study primary and secondary demands experienced by the family (Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994) to promote their well-being (Deatruck et al., 2014).

**Purpose/Objectives:** To examine the daily maternal caregiving demands for adolescent and young adult survivors of pediatric brain tumors who live with their families.

**Design:** A secondary analysis was conducted on interview data gathered during a large mixed-methods study that focused on perceived maternal caregiver competency and survivor health-related quality of life.

**Setting:** Home interviews.

**Sample:** A purposive sample of 46 maternal caregivers was selected from participants in the larger study.

**Methods:** Semistructured interviews were conducted with mothers. A directed content analysis was informed by Sullivan-Bolyai's framework describing the components of primary caregiving.

**Main Research Variables:** Caregiving demands.

**Findings:** Data regarding four main categories of maternal daily caregiving demands were identified from 25 of the 46 interviews: managing the illness; identifying, accessing, and coordinating resources; assisting with everyday responsibilities; and fostering psychosocial health.

**Conclusions:** Potential day-to-day management tasks or demands of mothers of adolescent and young adult survivors of pediatric brain tumors were identified.

**Implications for Nursing:** The major demands of caregiving are similar to those for children with other chronic conditions, with the addition of assisting with everyday responsibilities and fostering psychosocial health.

**Key Words:** caregiver tasks; pediatric brain tumors; caregiving demands; caregiving burden; parents; qualitative research

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Because frameworks do not exist for caregiving in families of young adults, child and adult caregiving frameworks are summarized according to the framework proposed by Sullivan-Bolyai et al. (2003, 2004). Primary caregiving demands include managing the illness and identifying, accessing, and coordinating resources. Secondary caregiving needs include maintaining the family unit and maintaining self.