

Symptoms, Coping, and Quality of Life in Pediatric Brain Tumor Survivors: A Qualitative Study

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Pediatric brain tumors are the most common solid neoplasm in children (Faria, Rutka, Smith, & Kongkham, 2011). From 2001–2005, 4,181 children aged 0–14 years were diagnosed with cancer in Canada, and 676 died from this disease (Ellison, De, Mery, & Grundy, 2009). The incidence of primary pediatric brain tumors is about 2.76–4.28 cases per 100,000 children (Maher & Raffel, 2004). As more children survive cancer, the need for long-term monitoring and follow-up care continues to grow (Ellison et al., 2009).

Current management strategies for children diagnosed with brain tumors aim to optimize long-term survival in children with high-risk tumors, while maintaining high survival rates in children with low-risk disease (Pollack, 2011). Treatment for pediatric cancers usually involves one or more of three main modalities: localized surgical resection, radiation therapy, and/or chemotherapy. The trend in neurosurgery for pediatric neuro-oncologic conditions has been toward less invasive procedures and non-surgical interventions, where possible (Mainprize, Taylor, & Rutka, 2000), because treatment toxicities are cumulative (Eiser, 2004). The outcomes for children diagnosed with and treated for cancer are largely dependent on host factors, the type of cancer diagnosed, timing, and treatments received (Bhatia & Landier, 2005). Aggressive therapy often is needed to cure this potentially lethal disease; however, late effects, such as injury to the developing brain, remain a profound concern (Walter & Hilden, 2004).

With surgical resection, craniospinal irradiation, and chemotherapy, cure rates as high as 85% can be achieved in average-risk cases; however, improved survival can affect quality-of-life (QOL) outcomes in survivors (Gottardo & Gajjar, 2008). Survivorship is conceptualized as the phase of cancer care that begins after the completion of definitive therapy (Grunfeld & Earle, 2010). Brain tumor survivors include children

Purpose/Objectives: To explore the symptom experience, coping strategies, and children's descriptions of their quality of life (QOL) after treatment for a brain tumor.

Research Approach: An interpretive descriptive qualitative study.

Setting: A pediatric hospital setting in Ontario, Canada.

Participants: 12 children aged 9–18 years.

Methods: Content analysis of semistructured interviews was guided by interpretive description methodology.

Findings: Children described symptoms including feeling tired, pain, headaches, emotional problems, difficulty thinking and remembering, problems with sleep, physical problems, and weight changes. Symptoms interfered with physical activity, keeping up with school, maintaining appearances, and communication. Coping strategies included reconditioning, taking breaks, taking medication, challenging themselves, volunteering, maintaining friendships, laughing, and using aids.

Conclusions: Survivors experienced multiple symptoms that had an effect on their life, but overall, they described good QOL.

Interpretation: Caregivers need to understand the complexity of their patient's symptom experience and its impact on his or her daily life. Coping strategies can be identified to help mitigate potentially negative QOL outcomes.

Key Words: pediatric oncology; neurologic malignancies; nursing research qualitative; quality of life; survivorship

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and youth who have completed treatment for a brain tumor and who have received surgery, chemotherapy and/or radiation therapy. Cure from this disease can come at a high price in terms of late effects that may impair long-term QOL (Pollack, 2011). Treatment for children with brain tumors can result in many neurologic complications, such as neurocognitive problems that can affect daily function (Monje & Fisher, 2011). Brain tumors and their treatments in children result