

Meaning Making and Religious Engagement Among Survivors of Childhood Brain Tumors and Their Caregivers

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PURPOSE: To describe how adolescent and young adult survivors and their mother-caregivers ascribe meaning to their post-brain tumor survivorship experience, with a focus on sense making and benefit findings and intersections with religious engagement.

PARTICIPANTS & SETTING: Adolescent and young adult survivors of childhood brain tumors and their families, living in their community settings.

METHODOLOGIC APPROACH: Secondary analysis of simultaneous and separate individual, semistructured interviews of the 40 matched dyads (80 total interviews) occurred using conventional content analysis across and within dyads. Meaning is interpreted through narrative profiles of expectations for function and independence.

FINDINGS: Participants made sense of the brain tumor diagnosis by finding benefits and nonbenefits unique to their experiences. Meaning was framed in either nonreligious or religious terms.

IMPLICATIONS FOR NURSING: Acknowledging positive meaning alongside negative or neutral meaning could enhance interactions with survivors, caregivers, and their families. Exploring the meaning of their experiences may help them to reconstruct meaning and reframe post-tumor realities through being heard and validated.

KEYWORDS meaning making; childhood brain tumor; religious engagement; survivorship

ONF, 46(2), 170–184.

DOI 10.1188/19.ONF.170-184

The sequelae of treatment for survivors of childhood brain tumors radically recast survivors' physical, cognitive, and psychosocial realities (Turner, Rey-Casserly, Liptak, & Chordas, 2009). Many children diagnosed with a brain tumor live into adulthood because three-quarters survive at least five years after treatment without evidence of disease recurrence (Noone et al., 2018). They generally do so in families and often with one parent (usually the mother) acting as primary caregiver in addition to assuming regular parenting responsibilities. Parents and survivors often experience diagnosis- and treatment-related post-traumatic stress symptoms during survivorship (Bruce, Gumley, Isham, Fearon, & Phipps, 2011). Parents of survivors of childhood brain tumors are caregivers for many years during and after treatment, and they undergo reevaluations of their understandings of and expectations for their and their children's lives. They frequently and consciously seek to understand their daily lives and the stark changes in the child's life, in the family members' lives, and in their expectations of their child, the family, and themselves. These changes can be productively understood through meaning making, and they often interact with an individual's or family's religious engagement.

Background

Meaning Making

Meaning making, theoretically refined by Park (2010), is used by individuals and families as they reorient themselves following stressful life experiences. Meaning making was originally defined by Park and Folkman (1997) as a model of coping that distinguishes between specific, appraised, and contextual experiences and a global meaning that reflects one's understanding of reality in general. It unites global