

Perceived Stress and the Fatigue Symptom Cluster in Childhood Brain Tumor Survivors

Ann Hammack Johnson, PhD, APRN, CPNP-PC, Marti Rice, PhD, RN, FAAN,
Anne Turner-Henson, PhD, RN, FAAN, Joan E. Haase, PhD, RN, FAAN, and Andres Azuero, PhD

OBJECTIVES: To explore and estimate relationships among the elements of the symptom cluster in survivors of brain tumors aged 8–12 years during early survivorship.

SAMPLE & SETTING: Child participants completed treatment at least six months and less than six years prior to enrollment at Children's Hospital of Alabama in Birmingham or Cook Children's Medical Center in Fort Worth, Texas.

METHODS & VARIABLES: With cross-sectional methods, the authors measured child-perceived stress, sleep-wake disturbance (SWD) (parent report), and fatigue. Children also provided saliva samples for cortisol measurement (stress response) and completed actigraphy sleep monitoring.

RESULTS: Mild to moderate stress, SWD, and fatigue were reported, and a wide range of sleep times and cortisol levels were noted. Meaningful effect sizes in relationships between variables were found.

IMPLICATIONS FOR NURSING: The stress, SWD, and fatigue symptom cluster in survivorship necessitates routine nursing assessment.

In 2015, 21,894 children aged 0–19 years were living with primary brain and other central nervous system (CNS) tumors in the United States, with an estimated 49.4 per million diagnosed from 2011–2015. During this time, survival rates have increased to about 75% (National Cancer Institute [NCI], 2017b). This emerging population has potentially serious or burdensome long-term health effects from cancer and cancer treatment (Hobbie et al., 2016; Meeske, Patel, Palmer, Nelson, & Parow, 2007). Common symptoms and symptom clusters, such as psychological stress, sleep-wake disturbance (SWD), and fatigue, have been noted in children and adolescents on and off treatment for a variety of malignancies, including CNS, leukemia, and solid tumors (Gordijn et al., 2013; Olson, 2014; Tomlinson et al., 2016). Similar findings have been seen in adolescent and young adult survivors of non-CNS malignancies (Daniel et al., 2016; Desaulniers et al., 2015). Few studies explore biobehavioral interactions within the stress, SWD, and fatigue symptom cluster, particularly in childhood brain tumor survivors (Gordijn et al., 2012). Findings from the large longitudinal Childhood Cancer Survivor Study indicate that psychological distress predicts fatigue and SWD and that there is a 30% greater chance of childhood brain tumor survivors having comorbid distress (both affective and somatic) in adulthood compared to survivors of other childhood cancers (D'Agostino et al., 2016). In childhood, fatigue and related symptoms of SWD and stress also have been seen in survivors of acquired and traumatic brain injury and are correlated with lowered quality of life and functioning (Crichton et al., 2018; Wilkinson et al., 2018).

The study of psychological and physiologic stress is important in the exploration of related symptom clusters, aligns with the goals of symptom science research, and can improve care after treatment for childhood brain tumors (Miaskowski et al., 2017). A biobehavioral perspective provides a multidimensional

KEYWORDS childhood; cancer; survivorship; stress; sleep; fatigue; symptom cluster; brain tumor

ONF, 45(6), 775–785.

DOI 10.1188/18.ONF.775-785