This material is protected by U.S. copyright law. To purchase quantity reprints, e-mail reprints@ons.org. For permission to reproduce multiple copies, e-mail pubpermissions@ons.org.

A Model Linking Uncertainty, Post-Traumatic Stress, and Health Behaviors in Childhood Cancer Survivors

Ya-Ling Lee, DNSc, RN, Bih-Shya Gau, PhD, RN, Wen-Ming Hsu, PhD, MD, and Hsiu-Hao Chang, MD

lthough the overall rate of long-term survival has improved worldwide, cancer remains the leading cause of death among children aged 1–14 years in the United States (American Cancer Society, 2008). Young people with cancer may experience uncertainty (Koocher, 1985; Santacroce, 2003; Santacroce & Lee, 2006) and psychosocial distress (Kazak et al., 2004) about whether they will survive the primary cancer and whether they will develop medical late effects of cancer and treatment in survivorship (Greving & Santacroce, 2005; Pagano-Therrien & Santacroce, 2005). Given the increasing rates of long-term survival following a childhood cancer diagnosis, a model for understanding survivors' responses to childhood cancer and treatment should be developed. A greater understanding of survivors' health behaviors in particular can act as the first step to developing a means to change behaviors that may increase the risk for late effects and, therefore, affect survivorship.

Late effects are the chronic adverse consequences of a disease and its treatment. Young people who survive primary cancer because of the use of aggressive multimodal treatments are at heightened risk for late effects, which is an additional source of uncertainty and psychological distress. Seven of 10 survivors develop at least one medical late effect, and 50% of survivors with late effects present with disabilities that adversely alter quality of life (Dreyer, Blatt, & Bleyer, 2002). Late effects of childhood cancer can include the development physical impairments and second malignancies, which significantly increase the risk of developing breast, central nervous system, bone, thyroid, lung, and skin cancers and acute nonlymphocytic leukemia after Hodgkin disease treatment with chest irradiation (Dickerman, 2007; Guerin et al., 2003; Inskip & Curtis, 2007; Laurie et al., 2002; Maule et al., 2007; Mertens et al., 2002; Sklar et al., 2000; van Leeuwen et al., 2000).

Purpose/Objectives: To consolidate the literature and provide a model to explain the links among uncertainty, post-traumatic stress syndrome, and health behaviors in adolescent and young adult childhood cancer survivors.

Data Sources: A systemic review of related literature and theory was used for the proposed model. The literature pertaining to the Uncertainty in Illness Theory, childhood cancer late effects, post-traumatic stress, and health behaviors was reviewed and critiqued from three data sets from 1979–2007: MEDLINE®, PsycInfo, and CINAHL®. Key words used for the search were uncertainty and post-traumatic stress as well as health behaviors, including smoking, alcohol use, unsafe sex, sunscreen use, and physical inactivity.

Data Synthesis: Childhood cancer survivors living with chronic uncertainty may develop a new view of life and, as a result, adopt more health-promotion behaviors and engage in less health-risk behaviors. However, survivors living with chronic uncertainty may generate symptoms similar to post-traumatic stress disorder and, therefore, adopt fewer health-promotion behaviors and engage in more health-risk behaviors.

Conclusions: The uncertainty that pervades the childhood cancer experience can lead to the development of symptoms that resemble those of post-traumatic stress. The symptoms can interfere with the adoption of healthy lifestyle behaviors and avoidance of health-risk behaviors.

Implications for Nursing: The theoretically derived model outlined in this article can be used to guide clinical interventions and additional research into the health behaviors of childhood cancer survivors.

Childhood cancer survivors have a 10–15 times greater risk for second malignancy than that of age-matched controls (Neglia et al., 2001) and about six-fold greater than the general population (Inskip & Curtis). Five-year childhood cancer survivors have a 10.8 times greater risk than that of the general U.S. population for overall mortality (Mertens et al., 2001). Physical impairments include pulmonary fibrosis, cardiac disease, infertility, metabolic syndrome, obesity or being