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The Symptom Cluster Experience Profile Framework

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Five-year survival rates for most childhood cancers are approaching 82% (Altekruse et al., 2010), and more than 225,000 adult survivors of childhood cancers were living in the United States in 2009 (Mariotto et al.). According to emerging evidence, adult survivors are highly vulnerable to late effects (e.g., physical and psychological complications, disabilities, adverse outcomes) that persist or arise after completion of cancer treatments (Children's Oncology Group, 2008; Hewitt, Weiner, & Simone, 2003). Many late effects are life threatening (e.g., recurrence of primary cancers, secondary cancers, cardiovascular and pulmonary complications) (Bowers et al., 2005, 2006; Mertens et al., 2001, 2002, 2008; Neglia et al., 2001; Oeffinger et al., 2006) and clearly result from previous cancer therapies. Other late effects are chronic health conditions (e.g., hypothyroidism, diabetes, coronary artery disease) that result from complex interactions among previous cancer therapies, stressors, lifestyle behaviors, and family history (Geenen et al., 2007; Oeffinger et al., 2006). As part of the Childhood Cancer Survivor Study (CCSS), numerous investigators have identified subgroups of adult survivors of childhood cancers who are at high risk for organ toxicities and secondary cancers, and risk-based screening recommendations have been developed to optimize outcomes in these high-risk subgroups (Hudson et al., 2009).

Although understudied in adult survivors of childhood cancers and not necessarily linked empirically to specific organ-system impairments, subgroups of adult survivors who are at high risk for excess symptom burden should be identified. Alarming, unrelieved symptoms in adult survivors of childhood cancers have been associated with negative and potentially fatal consequences. For example, the combination of unrelieved pain and psychological distress was significantly associated with suicidal ideation or past suicidal attempts (Recklitis, Lockwood, Rothwell, & Diller, 2006), and actual suicide rates for cancer survivors are twice that of

Purpose/Objectives: To present the novel Symptom Cluster Experience Profile (SCEP) framework for guiding symptom research in adult survivors of childhood cancers and other subgroups at risk for high symptom burden.

Data Sources: Empirically derived model of symptom cluster experience profiles, existing theoretical frameworks, and data-based literature on symptoms and quality of life in adult survivors of childhood cancers.

Data Synthesis: In a previous study, the authors generated a preliminary model to characterize subgroups of adult survivors of childhood cancers with high-risk symptom cluster profiles. The authors developed the SCEP framework, which depicts symptom cluster experiences as subgroup-specific profiles that are driven by multiple sets of risk and protective factors. The risk and protective factors may directly and indirectly contribute to or alleviate symptoms through their effects on systemic stress. Systemic stress instigates and sustains the symptom experience that, in turn, is expressed through negative diffusion into other components of quality of life, such as functional status, general health perceptions, and overall quality of life.

Conclusions: The SCEP framework is an initial approach to unbundle the complex heterogeneity that underlies the clustering of symptoms. By measuring a wide range of risk and protective factors in future studies of adult survivors of childhood cancers and other subgroups at risk for high symptom burden, further development and validation of the SCEP framework will occur.

Implications for Nursing: The SCEP framework can be used to specify mechanisms underlying symptom cluster profiles and derive interventions targeted to high-risk symptom profiles. Findings from future studies can be translated to risk-based surveillance and symptom management clinical practice guidelines.

the general population nationally (Misono, Weiss, Fann, Redman, & Yueh, 2008).

Among adult survivors of childhood cancers from the CCSS, 10%–23% reported moderate to extreme pain (Hudson et al., 2003; Lu, Tsao, Leisenring, Robison, & Zeltzer, 2007), 16%–40% significant fatigue (Hudson et al., 2003; Mulrooney et al., 2003, 2008), 12%–16% problems sleeping