

Health-Related Quality of Life in Childhood Cancer: State of the Science

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Purpose/Objectives: To summarize the theoretical understanding and empirical measurement of health-related quality of life (HRQOL) for childhood cancer survivors and to identify determinants of HRQOL for adolescents with cancer.

Data Sources: Published articles from 1985–2005. Key words included health, quality of life, childhood cancer, and survivorship.

Data Synthesis: Direct and indirect determinants of HRQOL for adolescents with cancer include physical health, perceived level of self-esteem, coping abilities, personality characteristics, hopefulness, social support, and overall experiences during treatment.

Conclusions: Understanding and influencing children's and adolescents' experiences in treatment have been suggested as keys in ameliorating psychosocial sequelae and positively influencing HRQOL in survivorship.

Implications for Nursing: Psychosocial nursing care interventions are needed to positively influence the determinants of HRQOL for children and adolescents with cancer.

Key Points . . .

- ▶ Two common and significant goals of children and adolescents with cancer are to be healthy and get on with life, which have implications for their health-related quality of life (HRQOL) in survivorship.
- ▶ Research has suggested that the perception of psychosocial well-being influences physical functioning and treatment outcomes among children and adolescents with cancer and that experiences during treatment and individual responses to treatment have an effect on HRQOL in survivorship.
- ▶ Because healthcare professionals have frequent contact with children and adolescents during treatment, multiple opportunities exist for facilitating ongoing psychosocial development and functioning and fostering a positive sense of well-being, which have implications for patients' overall treatment outcomes and quality of life in survivorship.

Currently 270,000 adult survivors of childhood cancer in the United States are considered to be at high risk for medical and psychosocial sequelae that can adversely affect their health status (Hewitt, Weiner, & Simone, 2003). The Childhood Cancer Survivor Study (CCSS), a longitudinal cohort study funded by the National Cancer Institute (NCI), tracked the outcomes of 14,000 long-term survivors of childhood cancer diagnosed at 1 of 26 participating institutions from 1970–1986 (Hudson et al., 2003). Findings from the study have yielded substantial information about the emerging clinical population. Mertens et al. (2001) reported that subjects in the CCSS have an increased risk for early mortality as a result of secondary cancers and cardiac or pulmonary diseases caused by treatments received. In addition to the medical sequelae affecting physical functioning, findings from the CCSS have identified the substantial psychosocial risks that some adult survivors of childhood cancer may experience. Among the domains that could affect psychosocial functions, Hudson et al. assessed the mental health, cancer-related pain, and cancer-related anxieties or fears of 9,535 of the 14,000 survivors in the CCSS study. Among the sample of young adult survivors of childhood cancer, 17% had depressive symptoms, 10% reported moderate to extreme pain, and 13% expressed fears related to the cancer experience. The researchers concluded that the experience of childhood cancer for certain subgroups of adult survivors may produce chronic psychological and cognitive impairments that hinder adjustment and quality of life (QOL) and that the risk for adverse

health status is greatest among survivors who were female, individuals with a low educational level, and those with low household incomes.

Since the publication of the CCSS findings, new information about the physical sequelae and psychosocial functioning of childhood cancer survivors continues to be reported. Findings from early studies and current research on the psychosocial health of childhood cancer survivors are mixed. Some research suggests that survivors of childhood cancer experience psychological dysfunction and psychosocial delays (Koocher, O'Malley, Gogan, & Foster, 1980; Stam, Grootenhuis, & Last, 2005; Wiener et al., 2006). In contrast, other studies have reported that survivors score normal or near normal on standardized measurements of psychological health (Newby, Brown, Pawletko, Gold, & Whitt, 2000; Recklitis et al., 2006). Among the most recently published findings on the health-related QOL (HRQOL) of childhood cancer survivors, high perceptions of QOL (Boman & Bodegard, 2000; De Clercq, DeFruyt, Koot, & Benoit, 2004; Punyko et al., in press; Shankar et al., 2005) generally were noted. Zebrack

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