

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, Grootenhuys, & 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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and Zeltzer (2003) summarized discordant findings of earlier research by concluding that some survivors have managed to grow and develop in positive ways because of their cancer experiences and that most survivors are probably healthy and would score as normal on standardized tests of psychological functioning, yet a small but significant proportion of childhood cancer survivors experiences psychological or social adjustment difficulties.

NCI as well as other funding agencies have strongly recommended and, in some cases, required that outcome measures for cancer treatment include survivors' perceived level of HRQOL (Testa & Simonson, 1996). In addition, QOL has become an important outcome measure in clinical trials (Testa & Simonson). The call to measure HRQOL extends to children with cancer, wherein the understanding of the phenomenon is limited as compared to adult cancer populations. The need for QOL research among adult survivors of childhood cancer as an outcome measure of the cancer experience is compounded by the estimation that most of the individuals will live several decades after being cured during which they will have little or no contact with healthcare professionals (Parsons & Brown, 1998). Parsons and Brown highlighted that being a survivor, with or without long-term sequelae, will continue to affect some or all survivors' healthcare status.

The construct of HRQOL has gained importance as survival rates continue to improve. Zebrack and Zeltzer (2003) pointed out that despite many statistics that report survival rates of children and adolescents, the data provide no discussion of the QOL expected, enjoyed, or endured by the individuals. Zebrack and Zeltzer believed that success in pediatric oncology requires that researchers and clinicians who provide care for pediatric patients attend to survivors' psychosocial needs and QOL as well as consequences of successful treatment.

Conceptualization and Empirical Measurement

Within the adult-focused cancer literature, the number of articles that address the conceptualization and measurement of HRQOL has increased steadily; a significantly larger body of knowledge exists regarding HRQOL in the general healthcare literature. State-of-the-art research now emphasizes that HRQOL is a multidimensional, self-perceived construct that includes aspects of physical functioning and activity, psychological adjustment, social functioning and relationships, and overall sense of well-being (Bhatia et al., 2002). In a concept analysis of HRQOL, Sredl (2004) identified six major categories of HRQOL—physical, psychological, personality, environmental, social, and future orientation—that each contain subconstructs. The aspects of the phenomenon are multifactorial and interact with one another. As noted by Sredl, healthcare providers acknowledge that all aspects of a person's life affect the delicate balance of well-being known as QOL. Noll and Fairclough (2004) indicated the complexities of studying HRQOL specifically among survivors of childhood cancer and identified the main problematic issues to be (a) identification of the important facets of survivorship, (b) sustaining a focus that is inclusive of developmental shifts in essential life issues, and (c) general difficulties associated with HRQOL research and measurement.

Hinds, Burghen, Haase, and Phillips (2006) indicated that one of the advances in HRQOL for pediatric patients with

cancer has been in defining the construct from the perspective of children and adolescents undergoing treatment for their disease. Hinds et al. (2004) described the construct for patients with cancer receiving treatment as "an overall sense of well-being based on being able to participate in usual activities; to interact with others and feel cared about; to cope with uncomfortable physical, emotional, and cognitive reactions; and to find meaning in the illness experience" (p. 767). They also reported that pediatric patients with cancer need to maintain a positive perspective so they may self-sustain. Cognitive predictive coping, such as being optimistic and maintaining a positive perspective about the course of an illness, has a strong relationship with HRQOL among early survivors of childhood cancer (Stam, Grootenhuis, Caron, & Last, 2006). Stam et al. (2006) stressed that because having positive expectations about the future is an important predictor of HRQOL, interventions directed at enhancing positive expectations about the future should be useful for young survivors of childhood cancer.

Instruments

Although growth in the knowledge of HRQOL among pediatric patients with cancer lags behind the general healthcare literature and the literature regarding adult patients with cancer, Bradlyn (2004) noted that instrumentation to measure the phenomenon is no longer the formidable barrier that it once was and that appropriate measures are available to clinicians and researchers. Many instruments are found in the general pediatric healthcare literature to measure HRQOL, and several have been developed specifically for children with cancer or childhood cancer survivors. A description of three instruments developed specifically for pediatric patients with cancer and their psychometric properties is found in Table 1.

Meaning-Based and Function-Based Models

In a critical appraisal of the quality of QOL measurements in the general healthcare literature, Gill and Feinstein (1994) commented, "Since the 1970s, the measurement of quality of life has grown from a small cottage industry to a large academic enterprise" (p. 624). Despite the dramatic increase in the development of QOL measurements that, in general, reflect sound, rigorous scientific principles, the researchers questioned whether the measurements were satisfactory for the clinical goal of indicating what clinicians and patients perceive as QOL. Gill and Feinstein raised the issue that existing QOL measures do not incorporate patients' values and preferences. Gill and Feinstein's concerns reflect the limitations of function-based models to measure HRQOL. Function-based models operate from a biomedical model, which emphasizes physical functioning and the impact of long-term treatment effects on health status. In contrast, meaning-based models emphasize patterns and the treatment experience of cancer from a subjective and holistic perspective (Haase, Heiney, Ruccione, & Stutzer, 1999). Theoretical models explaining QOL among patients with cancer have been primarily function or meaning based (Costain, Hewison, & Howes, 1993). The issues in the measurement of HRQOL in the general healthcare literature discussed by Gill and Feinstein also have been raised by Haase et al. regarding adolescents with cancer. Haase et al. argued that when HRQOL instruments focus solely on function-based meaning, they may provide misleading and inaccurate information. The researchers described a compelling example of a function-based measure

Table 1. Health-Related Quality-of-Life Instruments for Children With Cancer and Childhood Cancer Survivors

Instrument	Author	Description	Reliability and Validity Data
Minneapolis-Manchester Quality-of-Life Instrument <ul style="list-style-type: none">• Youth Form (8–12 years)• Adolescent Form (13–20 years)• Young Adult Form (21–45 years)	Bhatia et al., 2002	A 32-item scale with four subscales to reflect physical functioning, physical symptoms, psychological functioning, and outlook on life	Internal consistency reliability for all items ranged from 0.72–0.80. Test-retest reliability was 0.72. Known groups validity was established between healthy subjects and patients with cancer; construct validity with the Child Health Questionnaire was reported with correlations between subscales on the two instruments ranging from 0.39–0.60.
Pediatric Oncology Quality-of-Life Measure	Goodwin et al., 1994	A 21-item multidimensional scale that measures three factors that can be used to compute a total score: role restriction and physical functioning, emotional distress, and response to current medical treatments. Items are rated on a 0–6 scale (never to sometimes) and provide a total score and subscores on the three factors.	Internal consistency coefficients for the three factors ranged from 0.68–0.87.
Pediatric Cancer Quality-of-Life Inventory <ul style="list-style-type: none">• Child Report (ages 8–12)• Teen Report (ages 13–18)	Varni et al., 1998	A 23-item Likert scale with four subscales to reflect physical, psychological, social, and cognitive functioning. Items are rated from 0–3 (never to always).	Internal consistency reliability for the instrument ranged from 0.91–0.92; the authors also reported multitrait and multimethod evidence data for the tool's construct validity.

that asks whether an adolescent attends school. If the adolescent answers “no,” the measure assumes decreased HRQOL. Haase et al. refuted that finding with data from a qualitative study in which some adolescents with cancer chose to stay at home to be with their families.

Normalcy, Being Positive, Hopefulness, and Health-Related Quality of Life

Pediatric oncology literature is limited, yet the body of knowledge that discusses the conceptualization and empirical measurement of HRQOL is expanding. Hinds (1990) suggested that a definition for HRQOL among children and adolescents with cancer may be difficult to define because it is a phenomenon that is the result of the dynamic interfacing of several related concepts, each of which is ever-changing in complexity, intensity, and expression. Hinds (1990) described QOL among children and adolescents with cancer as their subjective sense of well-being during their entire cancer experience.

The conceptualization of HRQOL within the general healthcare literature, offered by Holmes and Dickerson (1987), reflects Hinds' (1990) beliefs as well as what is known about adolescents' descriptions of the experience of living with cancer. Holmes and Dickerson defined HRQOL as an abstract and complex phenomenon representing individual responses to the physical, mental, and social factors that contribute to normal living. A common and significant goal of adolescents with cancer is to be normal (maintain normalcy) and get on with life. The phenomenon first was described in the literature by Rechner (1990), who conducted a phenomenologic study of five adolescents who had completed treatment or were receiving therapy for childhood cancer. The experience of living with cancer was unique for each adolescent; however, all shared common illness experiences that were described in an analytic framework with the overall theme of “getting on with life.” The adolescents responded to cancer by experiencing the illness and determining that they were normal; they developed a philosophy of being positive and redefined

their social worlds to get on with life. Since Rechner's study was published, adolescents' desire to maintain normalcy has been well documented in the literature and supported with quantitative and qualitative findings (Weekes & Kagan, 1994; Woodgate, 2005). In her study, Woodgate strongly supported Rechner's findings in which adolescents clearly expressed that, despite the amount of physical distress they experienced as well as the changes in their body image resulting from treatment that affected their perception of self, they tried not to view their experiences with cancer as completely negative and tried to make the best of things. Woodgate concluded that although the adolescents described the significance that cancer had on their lives, they described themselves as “still being pretty much the same.”

Making meaning and being positive were embedded in the essence of well-being among a sample of young adult survivors of childhood cancer. In a qualitative study conducted by Parry and Chesler (2005), making meaning and being positive were described as psychosocial thriving in which the processes of coping are related intimately to long-term psychosocial well-being among childhood cancer survivors. Parry and Chesler reported that the outcomes of the coping processes are psychosocial healing and growth and especially thriving.

In addition to being positive and redefining their worlds to maintain normalcy, adolescents who experience cancer employ the psychological cognitive processes of courage, resiliency, and hopefulness as strategies to manage the experience. The concepts are believed to affect the adolescents' view of their HRQOL. Understanding and positively influencing the coping strategies have been suggested as keys to ameliorating their psychosocial sequelae and, thus, influencing HRQOL in survivorship. The foundational and ongoing work by Hinds (1988, 2000, 2004) and other researchers has provided ample evidence that adolescents employ hopefulness as a coping strategy throughout the cancer experience. Hopefulness is a significant determinant of psychosocial adaptation among adolescent patients with cancer (Hinds & Martin, 1988), and a positive relationship between hope and psychosocial

functioning has been reported among healthy adolescents as well (Yarcheski, Scoloveno, & Mahon, 1994). Hopefulness covaries with self-esteem among healthy females (Cantrell & Lupinacci, 2004; Hendricks et al., 2000) and female adolescents with cancer (Cantrell & Lupinacci). In her ongoing work to understand the experience of cancer among children and adolescents, Hinds (1990) developed a meaning-based HRQOL model in which QOL is correlated closely with tasks of coping and adaptation and the outcomes of adaptive processes are empirical indicators of the phenomenon for pediatric patients with cancer and survivors. Hinds (1990) hypothesized relationships among the constructs of physical, psychological, and social or role functioning to explain the construct of QOL.

Through a series of 11 studies using research triangulation methodology, Haase et al. (1999) developed a meaning-based model of HRQOL, the Adolescent Resilience Model, which has provided substantial insight into adolescents' experiences with cancer treatment, survivorship, and HRQOL. Within the program of research, six model generation studies were conducted, primarily with qualitative methods, and five model evaluation studies. The culmination of the studies was the pilot testing of an intervention, based on the Adolescent Resilience Model—Version 2, to develop psychosocial-focused nursing plans of care. The model is based on the perspectives of lifespan development and meaning-based models and contains concepts that are classified as protective risk, risk, or outcome factors (Haase, 2004). The outcome factors are resilience and QOL that encompass the phenomenon of well-being. The model not only offers a meaning-based theoretical perspective by which to study HRQOL among adolescents with cancer and young adult survivors of childhood cancer, but it also provides a basis for theory-based psychosocial nursing care interventions.

Yeh (2002) conducted a study among 116 Taiwanese pediatric patients with cancer (i.e., ages 7–18 years) to construct a theoretical model to explain HRQOL. For the children undergoing active therapy, their HRQOL included five domains: physical, disease or treatment symptom, psychological, cognitive, and peer functioning. Yeh reported that communication with others, severity of illness, and age provided a reliable explanation for the biopsychosocial responses of their HRQOL, which was hypothesized to impact the disease, treatment, and children's appraisal and satisfaction.

Health-Related Quality-of-Life Assessment of Childhood Cancer Survivors

Empirical literature on QOL among childhood cancer survivors, particularly survivors in the CCSS, is emerging. Published studies suggest that the individuals generally report high levels of QOL perceptions. Among 417 survivors of rhabdomyosarcoma enrolled in the CCSS, most were successful in attaining life goals despite an increased number of physical impairments compared to their siblings (Punyko et al., in press). Likewise, in a comparison group study that examined personality traits and QOL among survivors of childhood cancer and healthy controls, childhood cancer survivors reported higher levels of QOL than healthy children did (De Clercq et al., 2004). De Clercq et al. concluded that personality traits (i.e., being less neurotic and more consci-

entious) contributed to QOL and suggested that personality significantly influences children's QOL beyond a negative life event such as surviving cancer.

In a sample of 176 childhood cancer survivors, aged 16–28 years, the majority of the survivors experienced positive QOL in which they rated themselves high on happiness, feeling useful and satisfied with life, and their ability to cope as a result of having had cancer (i.e., being resilient) (Zebrack & Chesler, 2002). Survivors' perceived degree of hopefulness was tempered by uncertainty about their futures and fears about a second cancer. Psychological well-being was influenced most strongly by physical health status and living arrangements, whereas social QOL was related to physical health status and age at which cancer was diagnosed. Zebrack and Chesler posited that interruptions in expected social opportunities (e.g., missing school or social functions), especially during adolescence, influenced some childhood cancer survivors' QOL. The disruptions in their daily normal living (being normal) seemed to have significant implications for their HRQOL. Santacroce and Lee (2006) also reported the phenomenon of uncertainty among survivors of pediatric cancer. In their study, uncertainty mediated the relationship between post-traumatic stress syndrome and health promotion behaviors among 46 young adult survivors of childhood cancer. Santacroce and Lee suggested that to protect the future health and QOL of survivors, methods of coping with uncertainty should be taught.

In a cross-sectional, case-controlled study, 30 young adult survivors of childhood cancer were compared with healthy control subjects, matched for gender, age, and geographic location as well as general population norms on education, vocation, living arrangements, family or partner relationships, parenthood, and leisure activities (Boman & Bodegard, 2000). The researchers concluded that the social, vocational, and educational adjustment of childhood cancer survivors has a minimal to moderate effect on their cancer experience. Boman and Bodegard also reported that the treatment intensity and, even more significantly, the survivors' coping abilities with their illness experiences influenced their ability to reach long-term social goals. A longer duration in the treatment of cancer was associated with survivors reporting a lower socioeconomic level. In addition, survivors who reported poorer psychological coping with the illness and treatment lived in their parents' homes, had a shortened education, and had a lower socioeconomic level.

Among a sample of 64 survivors of childhood cancer residing in Israel who were compared with a sample of healthy controls matched for age, gender, and parental education levels, no evidence of increased incidence of psychological maladjustment or pathology existed (Dolgin, Somer, Buchvald, & Zaizov, 1999). Both groups completed a structured interview and the Mental Health Inventory. In addition, the medical charts of the childhood cancer survivors were reviewed. Dolgin et al. found that the sample of childhood cancer survivors was integrated into the social mainstream in terms of the HRQOL dimensions of education and significant relationships with others, yet the survivors reported that their health was significantly poorer compared to healthy controls ($p < 0.001$). The survivors' beliefs about having had cancer negatively influenced their employment histories and recruitment into military service.

In their assessment of HRQOL among school-aged children undergoing cancer treatment and healthy controls,

Shankar et al. (2005) reported that off-therapy survivors had a significantly higher overall HRQOL compared to healthy controls; the subgroups of males, survivors of non-neurologic solid tumors, and survivors who had been diagnosed with cancer more than six years before the study reported higher overall HRQOL scores when compared to healthy controls. Shankar et al. reported no differences in physical functioning and outlook on life between the survivors and healthy controls; in fact, cancer survivors had significantly higher psychological functioning and physical symptoms scores than healthy controls ($p \leq 0.001$). The findings were not explained, but previous studies (Apajasalo et al., 1996; Elkin, Phipps, Mulhern, & Fairclough, 1997) were cited that also reported off-therapy survivors experiencing higher QOL than healthy controls.

Direct and Indirect Determinants of Health-Related Quality of Life for Adolescents With Cancer

Research has suggested several direct and indirect determinants of HRQOL in adolescent cancer survivors such as physical health, perceived level of self-esteem, coping abilities, hopefulness, social support, and overall experiences during treatment, yet how the constructs collectively potentiate or hinder QOL is largely unknown. Researchers have considered whether objective factors such as age, gender, and intensity of treatment are more salient predictors of QOL than subjective factors. The findings of existing studies are mixed. Predictors of post-traumatic stress symptoms among survivors have been gender, number of months off treatment, and subjective appraisal of anxiety level rather than objective factors such as medical sequelae of treatment (Stuber et al., 1997). In other studies, survivors' concerns for their health have not been shown to be influenced by gender, socioeconomic status, or length of time off therapy (Mulhern et al., 1995). In contrast, Langeveld, Grootenhuis, Voute, de Haan, and van den Bos (2004) reported that, among adult survivors of childhood cancer, being female, having a lower educational level, being unemployed, and being a survivor of leukemia or non-Hodgkin lymphoma without radiation and severe late effects or health problems were factors associated with post-traumatic stress syndrome. Finally, Schnoll, Knowles, and Harlow (2002) found that among 109 survivors of adult cancer, age and time since diagnosis were not correlates of adjustment, yet income level was associated with better adjustment. Thus, research needs to further delineate the determinants of QOL among adolescent survivors of cancer.

Psychosocial Development and Adaptation

The experience of cancer and having a chronic illness during adolescence influences emotional, cognitive, physical, social, and spiritual development and, thus, creates additional challenges for individuals to master developmental tasks and acquire effective coping abilities (Enskar, Carlsson, Golsater, & Hamrin, 1997; Keller & Nicolls, 1990; Nelson, 2004; Ritchie, 1992). Despite the challenges, most adolescents meet developmental tasks, strive to maintain normalcy, and wish to get on with their lives throughout the cancer experience (Rechner, 1990; Ritchie, 2001; Weekes & Kagan, 1994). Developmental

task resolution during adolescence has consequences for psychosocial adjustment in early adulthood and survivorship. Self-esteem is a significant predictor of later psychosocial adjustment among adult survivors of childhood cancer (Overbaugh & Sawin, 1992). Conversely, success or failure in achieving developmental tasks during adolescence is a predictor of adaptation in young adults with cancer.

Survivorship and late treatment effects can pose a unique set of potential physical and psychosocial threats to the self-esteem of adolescent cancer survivors. Identified challenges for survivors are (a) returning to school and forming relationships, (b) poor academic performance, (c) employer prejudice, (d) insurance denial, and (e) permanent disfigurement (Evans & Radford, 1995). However, no overall difference existed between a group of survivors and a group of survivors' siblings on measures of self-esteem, school performance, employment status, and social or interactive abilities (Evans & Radford). Survivors in the study were coping well and achieving the same lifestyle goals as their siblings, although 36% of the survivors did experience residual physical mobility problems and many did not advance to higher levels of education. Other investigators who have measured self-esteem among cancer survivors reported their scores to be comparable to healthy peers (Gray et al., 1992; Olson, Boyle, Evans, & Zug, 1993). In contrast, in a more recent study of adult survivors of childhood leukemia and sibling controls, global self-worth was significantly lower in survivors (Seitzman et al., 2004). Interestingly, 81% of the survivors had a positive self-concept, although certain subgroups of survivors (i.e., those unemployed or of ethnic minority groups) were most vulnerable to a negative self-concept.

In the only published study found on the relationship between self-esteem and QOL among young adult survivors of childhood cancer, Langeveld et al. (2004) reported that measurements on the constructs in long-term survivors did not differ from their peers. Although not statistically significant, survivors' mean scores for measured variables were generally higher (indicating better HRQOL) than healthy participants'. A lower sense of self-esteem was associated with poorer QOL among the young adult survivors.

Coping styles and abilities of adolescents with cancer have been found to vary as a function of psychosocial maturity (Goertzel & Goertzel, 1991). An enhanced self-image is associated with greater capacity to adjust to stressors among adolescents with cancer (Stern & Alvarez, 1992). Varni, Katz, Colegrove, and Dolgin (1994) reported that higher perceived stress predicted psychological distress and lower self-esteem among adolescent cancer survivors.

Among healthy adolescent samples, research results have provided strong evidence that age and gender mediate the relationship between psychosocial development and coping (Frydenberg & Lewis, 1993; Groer, Thomas, & Schnoffer, 1992). Gender differences along with age are important factors influencing self-image and coping abilities (Stern & Alvarez, 1992). However, the mediating effects of age and gender on coping abilities have been inconsistent among samples of adolescents with cancer. Gender but not age and disease status mediated the perceived level of self-esteem or hopefulness among a sample of 90 adolescents, 45 of whom were experiencing cancer and a matched cohort group of 45 healthy adolescents (Cantrell & Lupinacci, 2004). Likewise, self-image did not vary among adolescents with cancer and

healthy adolescents as a function of age and gender (Stern, Norman, & Zevon, 1993). Spirito, Stark, Gil, and Tyc (1995) reported gender but no age effects on coping abilities among a sample of children and adolescents with chronic illness. The experience of cancer may mitigate any gender and age effects on self-image (Stern et al.). Despite the lack of clarity regarding the effects of age and gender on developmental task resolution in adolescents with cancer, their inclusion remains salient in this area of research.

Role Functioning and Social Support

Social support has been identified as a significant determinant of coping abilities (Thoits, 1986) and a coping resource (Bennett, 1993). Developmental theory suggests that adolescents broaden their social support systems to include peers rather than exchange their social support systems to exclude parents. Chronically ill children may have more restricted social support systems and different needs for support systems compared to healthy peers (Ellerton, Stewart, Ritchie, & Hirth, 1996). In a critical analysis of the literature on social support, psychosocial development, and coping among pediatric patients with cancer, Katz and Varni (1993) concluded that social competence (i.e., the perceived ability to be accepted by peers) is a major component of overall self-esteem; children with limited support systems, such as those with cancer, are at risk for long-term psychosocial maladjustment; and social support and social competence are crucial factors in coping and adjustment in children with cancer. Social support and psychosocial adaptation have been shown to have a positive relationship among adolescents with cancer. Adolescents who report more social support also report less psychological distress or higher coping scores (Neville, 1998; Nichols, 1995). Perceived social support and well-being also have been found to have a statistically significant positive correlation ($r = 0.55$, $p < 0.001$) among healthy adolescents (Yarcheski et al., 1994). Among survivors of adult forms of cancer, correlates of adjustment were found to have higher levels of social support, optimism, and meaning in life and lower levels of avoidance-type coping behaviors (Schnoll et al., 2002).

Physical Health Status

Although most survivors have not reported major difficulties in social competence or overall coping, some have experienced adjustment difficulties related to poor body image (Madan-Swain et al., 1994). The long-term effects of cancer treatment on body image and physical health status remain a special concern for cancer survivors who have been permanently disfigured by treatment. For example, adolescents who have experienced radical amputation or limb salvage surgery for treatment of osteogenic sarcoma of the lower leg have a decreased perceived level of QOL (Postma et al., 1992). Survivors who underwent radical amputation have lower levels of self-esteem and isolation in their social lives as a result of their disabilities as compared to those who had limb salvage surgery. In addition, Hudson et al. (2003) examined adverse health status in 9,535 long-term survivors of childhood cancer and reported that 44% had at least one adversely affected health status domain among the six domains assessed.

In summary, research has suggested that the perception of psychosocial well-being influences physical functioning and treatment outcomes among adolescents with cancer and that adolescents' experiences during treatment and their responses

to the treatment experience have an effect on their HRQOL in survivorship. Personality characteristics and the nature of how adolescents cope and adjust during treatment also influence their HRQOL in survivorship. The components, in addition to factors related to economic status and level of education, have an interactive and multifactorial effect on the HRQOL of childhood cancer survivors.

Strategies to Influence Health-Related Quality of Life

HRQOL research must move beyond descriptive research, which has little effect in the care of adolescents, to the use of research-based interventions that address HRQOL issues conducted and trialed in the clinical setting (Bradlyn, 2004; Haase et al., 1999). Bradlyn supported his argument by citing several studies in which physicians have incorporated HRQOL literature into their information sharing with patients, which resulted in patients reporting improvements in their HRQOL (Varni, Seid, Knight, Uzark, & Szer, 2002). Other research has found the use of HRQOL information to be a beneficial intervention for patients and physicians (Detmar, Aaronson, Wever, Muller, & Schornagel, 2000; Detmar, Muller, Schornagel, Wever, & Aaronson, 2002). Hinds et al. (2006) suggested that a combined clinical and research approach be taken and proposed that knowledge gained from the measurement of pediatric patients' cancer-related QOL can be used to guide quality, effective care.

Monaco and Smith (2005) posited that happy, well-adjusted patients are more likely to successfully complete treatment and ultimately have better survival. The researchers described a case report of a 12-year-old survivor who was identified by the healthcare team as needing post-treatment counseling. Through outpatient counseling, the patient was able to drastically improve his HRQOL. Monaco and Smith stressed that healthcare providers' input during and after treatment can be critical in ensuring satisfactory QOL among pediatric patients with cancer. Because healthcare professionals have frequent contact with adolescents during treatment, multiple opportunities exist to facilitate ongoing psychosocial development and functioning to foster a positive sense of well-being, hopefulness, and less avoidance-type coping, all of which have implications for overall treatment outcomes and HRQOL in survivorship. An early study by Hinds (1988) describing the relationship between nurses' caring behaviors with hopefulness and healthcare outcomes in adolescents undergoing treatment for cancer provided empirical evidence that nurse-patient transactions promote positive patient outcomes. Hinds (1988) concluded that through psychosocial care interventions, termed interpersonal skills in the article, nurses can promote a more positive future view among adolescents undergoing therapy for cancer.

Awareness and development of evidence-based clinical practice guidelines are growing regarding the follow-up care of childhood cancer survivors in pediatric oncology centers as well as the general healthcare community. Information from the findings of research studies and clinical practice experiences of healthcare providers is expanding rapidly regarding how to screen and treat survivors at high risk for physical and psychosocial sequelae, as well the health promotion for survivors (Absolom, Eiser, Greco, & Davies, 2004; Hollen, 2000a, 2000b; Kadan-Lottick et al., 2005; Landier et al., 2004;

Nelson, 2003; Nelson & Meeske, 2005; Nirenberg, 2004; Oeffinger & Hudson, 2004; Recklitis, O'Leary, & Diller, 2003; Schwartz, 1999; Sherman, Cooke, & Grant, 2005). In contrast to that body of literature, less research exists that describes the psychosocial care of children and adolescents during cancer treatment and the effect of targeted psychosocial interventions on adolescents' HRQOL during therapy and into survivorship (Nelson, Haase, Kupst, Clarke-Steffen, & Brace-O'Neill, 2004).

Hinds et al. (2003) described the functional integration of nursing research into the medical and pediatric oncology cooperative group protocols of the Children's Oncology Group. They suggested several approaches for integrating nurse-focused research protocols into developing or existing clinical trials to foster positive HRQOL; they included information needs, social support building, maintaining normalcy, and coping with the day-to-day experiences of being in active therapy (Decker, Phillips, & Haase, 2004; Haase, 2004; Haase et al., 1999; Woodgate, 2005). Haase and Phillips (2004) suggested that research priorities for adolescents and young adults with cancer should focus on the meaning that adolescents derive from their cancer experiences throughout the trajectory from diagnosis through survivorship; psychosocial and developmental models that most accurately represent adolescents, which, in turn, will most effectively guide psychosocial research; sensitivity of existing psychosocial measures of their experiences; priority concerns and their preferred ways to effectively address their concerns; ways to improve communication with adolescents and young adults; and feasibility, cost, treatment, and psychosocial outcomes of targeted interventions. Some of the specific strategies in the literature suggest involving adolescents who are in active treatment in mental health promotion programs that focus on enhancing self-concept, self-evaluation, and self-exploration

(Woodgate). Finally, consensus statements published by Nelson et al. (2004) after a preconference workshop at the 25th annual conference of the Association of Pediatric Oncology Nurses can be used to guide future research and interventions to enhance resilience and QOL in adolescents with cancer.

Conclusions

This article has reviewed research findings to provide information for the development of interventions to enhance HRQOL, assessment of HRQOL in clinical settings, and future HRQOL research among children and adolescents receiving treatment and for childhood cancer survivors. In researching HRQOL among childhood cancer survivors as well as those in treatment, the developmental level and intensity of treatment must be considered, and measurements in assessing physical health status and functioning must reflect realistic norms for individuals (Haase et al., 1999; Parsons & Brown, 1998). Meaning-based models of HRQOL appear to provide the most effective approach to understanding and measuring HRQOL among the clinical populations. Theory-based psychosocial nursing care interventions to influence HRQOL through direct and indirect determinants are needed. Implementing psychosocial nursing care interventions to positively influence the determinants of HRQOL with a meaning-based conceptualization during the treatment and care of adolescents with cancer may be an effective way to influence HRQOL among adolescents as they experience young adulthood through ameliorating their psychosocial sequelae during treatment.

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