

Advances in Defining, Conceptualizing, and Measuring Quality of Life in Pediatric Patients With Cancer

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Purpose/Objectives: To describe the notable advances in defining, conceptualizing, and measuring quality of life (QOL) in pediatric patients with cancer since the 1995 Oncology Nursing Society's State-of-the-Knowledge Conference on QOL.

Data Sources: Published research, clinical papers, and hospital policies.

Data Synthesis: QOL ratings from children and adolescents are being solicited increasingly in research and clinical assessments during treatment and survivorship using various methods but are not solicited from terminally ill patients; qualitatively induced models of pediatric cancer-related QOL now are being tested using quantitative methods.

Conclusions: Children aged five years and older are able to report their cancer-related QOL; reliable and valid QOL instruments exist for all phases of treatment except end of life.

Implications for Nursing: Nurses can involve children and adolescents in rating their QOL for research and clinical purposes and can apply theory-based QOL models to direct care.

Knowing what comprises quality of life (QOL) for children and adolescents during cancer treatment, how to measure their QOL, and how to translate the findings into terms that benefit patient care could have significant implications for cancer clinical care, research, and policy development. Accurate, sensitive, and well-timed QOL measurements could be the determining factor in clinical situations when two treatments have similar survival outcomes but differing demands on the other aspects of patients' lives. Being able to clinically evaluate the QOL of children and adolescents will help to more completely assess the full immediate and later effects of existing or future anticancer therapies and other therapeutic interventions. Accurate, longitudinal clinical assessments of pediatric cancer-related QOL will identify the points in treatment that are most demanding, thus providing the design framework for intervention studies intended to prevent or reduce treatment demands on patients and their family members. A combined clinical and research approach to pediatric cancer-related QOL could help to identify the indicators of quality care for children and adolescents from the point of diagnosis to survivorship or the end of life. The purpose of this article is to describe the notable advances in defining, conceptualizing, and measuring QOL in pediatric patients with cancer since the Oncology Nursing Society's State-of-the-Knowledge Conference on QOL convened in

Key Points . . .

- Significant advances have occurred since the mid-1990s in defining, conceptualizing, and measuring pediatric cancer-related quality of life (QOL).
- Measuring a child's or an adolescent's cancer-related QOL has taken place at all points of treatment, including survivorship, but not at the end of life.
- Nurses can involve patients, parents, and staff proxies in estimating pediatric patients' cancer-related QOL and can use the ratings to guide care.

1995 with support from Amgen, Inc., USA and Amgen, Inc., Canada (King et al., 1997). Application of these advances to the care of pediatric patients with cancer also is addressed.

Advances in Defining Quality of Life

One of the advances in pediatric cancer-related QOL has been in defining this construct from the perspective of children or adolescents diagnosed with and receiving treatment for cancer. Previously, relevant research reports did not include a definition of pediatric QOL (Bradlyn, Harris, Warner, Ritchey, & Zaboy, 1993; Czyzewski, Mariotto, Bartholomew, LeCompte, & Sockrider, 1994) or, instead, provided a description that was derived from adult QOL perspectives or clinical observations (Barr et al., 2000; Seid, Varni, Rode, & Katz, 1999). More specifically, a definition of QOL as reported by the children or adolescents being treated for cancer had not been

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advanced. Since the State-of-the-Knowledge Conference, two pilot studies, one cross-sectional and the other longitudinal, were initiated to elicit patients' perspectives on QOL. Thirty-six pediatric patients with cancer aged 8–18 years responded to open-ended interview questions about their QOL during treatment. The responses to the interview questions were analyzed using a semantic content analytic technique, and the following definition of pediatric cancer-related QOL evolved: “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” (Hinds et al., 2004, p. 767). In addition, six dimensions of the definition were identified and defined: symptoms, usual activities, social and family interactions, health status, mood, and meaning of being ill. The latter dimension, defined as “wondering why he or she has cancer but assuming that there must be an important reason, and believing that a positive perspective will help to sustain him- or herself” (Hinds et al., 2004, p. 770), previously had not been reported in other published works. Six questionnaire items have been constructed from the meaning-of-being-ill interview data to comprise an operational measure for the newly identified subscale of pediatric cancer-related QOL. Currently, patients enrolled in one of three frontline therapeutic protocols at five pediatric cancer centers are completing the six items as part of a larger approach to measure QOL during and following cancer treatment. The advance in defining pediatric cancer-related QOL from the perspective of the child or adolescent is limited to patients in treatment; therefore, the applicability of the dimensions and their definitions to survivors of childhood cancer or patients at the end of life has not been established.

Additional recent advances in defining QOL for pediatric patients with cancer are provided in the qualitative research conducted by Woodgate and Degner (2003, 2004) and Woodgate (2005). Patients' changing perceptions of themselves across the trajectory of treatment were a major influence on their QOL or well-being. An inductively identified process labeled by the researchers as “keeping the spirit alive” represented the patients' efforts to live with cancer. Cancer-related symptoms precipitated changes in self-perceptions; the same symptoms were viewed as part of the entire cancer experience, in part, represented by a process labeled “getting through all the rough spots” (Woodgate & Degner, 2003). Cancer was described as profoundly affecting adolescents' sense of self, particularly with physical changes. However, self-understanding, perceived as a positive outcome, was reported by patients when facilitated by the presence and support of family, friends, and healthcare providers. Using an open-ended question such as, “Some kids with cancer have told me that since having cancer, things are different in their daily lives. How has it been for you?” was recommended as a way to help pediatric patients with cancer gain positive self-understanding (Woodgate, 2005).

Advances in Conceptualizing Quality of Life: Conceptual Frameworks

Available models depicting pediatric QOL in children and adolescents receiving treatment for cancer have been developed primarily through inductive processes involving qualita-

tive methods. At the time of the 1995 State-of-the-Knowledge Conference, a limited number of conceptual models had been derived inductively (Haase, Heiney, Ruccione, & Stutzer, 1999; Hinds, 1990; Hinds & Martin, 1988). Advances since the conference include the addition of one more qualitative mode (Woodgate, 1999) and the use of quantitative techniques to assess the relationships proposed in inductively developed models. One such model is the Adolescent Resilience Model (ARM) developed by Haase et al. (1999). In a recent test of the ARM with 201 adolescents and young adults with cancer, the independent variables of illness-related risk (i.e., symptom distress and uncertainty), social integration (i.e., relationships with peers and healthcare providers), and spiritual perspective explained variance in the proximal outcomes of hope-derived meaning (76%), positive coping (52%), defensive coping (23%), and family atmosphere (27%). The ARM also explained 67% and 63% of the variance in the distal outcomes of resilience and self-transcendence, respectively (Haase & Kintner, in review). The ARM is being used to guide a number of intervention studies, including a study of music therapy and coping in adolescents and young adults undergoing stem cell transplant.

Another inductively developed model now being tested using quantitative techniques is the Self-Sustaining Model for Adolescents (Hinds & Martin, 1988). Statistically significant support for theorized positive relationships among adolescent hopefulness, self-esteem, self-efficacy, and symptom distress has been found through quantitative methods (Hinds et al., 2000). This model and the ARM model focus on the patient only. Future model development and testing will be even more informative for pediatric cancer care if both patient and family perspectives as well as their interplay are depicted in the same conceptual model.

Models of QOL for children and adolescents who are living as survivors of childhood cancer or dying because of cancer were not available until the early 2000s and thus represent an advance in conceptualizing about pediatric cancer-related QOL. One QOL model of pediatric cancer survivorship centers around the syndrome of post-traumatic stress disorder (PTSD), which originally was used to describe symptoms associated with personally experiencing or witnessing a life-threatening event. The symptoms of PTSD are grouped into three categories: reexperiencing (recurrent distressful memories or dreams), avoiding or numbing (shunning talking or thinking about the event), and increased arousal (behavioral or cognitive problems, sleep disturbances) (Taieb, Moro, Baubet, Revah-Levy, & Flament, 2003). Santacroce (2003) theorized on the basis of a comprehensive literature review that this syndrome is relevant for parents of children and adolescents diagnosed with cancer because of the severity of the uncertainties associated with the diagnosis and treatment. She noted that the uncertainties might differ by culture and religious beliefs. Santacroce proposed that cognitive behavioral therapy might benefit parents' emotional response to their child's illness experience and could indirectly benefit the adaptation to the illness by the ill child and well siblings. Kazak et al. (2004) reported descriptive findings of equal rates of PTSD symptoms in fathers and mothers of survivors of pediatric cancer, primarily in the symptom categories of arousal and reexperiencing; however, Stuber, Kazak, Meeske, and Barakat (1998) acknowledged that symptoms similar to PTSD are not a normative response during or following treatment.

Most recently, Phipps, Long, Hudson, and Rain (2005) challenged the conclusion that parents and pediatric patients with cancer experience PTSD. In a cross-sectional design based on the time since diagnosis, the investigators measured PTSD-associated symptoms in 162 patients and parents. They concluded that parent and patient reports of patients' QOL are consonant and that PTSD-like symptoms are more likely to be experienced shortly after the initiation of treatment rather than at later times during or following treatment. Phipps et al. (2005) and Langeveld, Grootenhuis, Voute, and de Haan (2004) reported a low incidence of PTSD symptoms in patients and parents and questioned the appropriateness of the model to explain adaptation to childhood cancer or QOL in survivorship. Future research is needed to determine the validity of the PTSD model in patients and parents. Central to the model are symptoms and a syndrome related to post-traumatic stress; therefore, the model's emphasis is on the vulnerability of the survivors and their family members and not on the potential positive aspects of survivorship on QOL. Further explorations of the full range of factors influencing the QOL of survivors and related outcomes are recommended. A model applied to survivors of childhood cancer that considers a broader set of variables that potentially influence survivors' QOL is the Interaction Model of Client Health Behavior (Cox, 2003). In addition, the emerging concept of post-traumatic growth being examined in adult patients with cancer (Cordova & Andrykowski, 2003) may be a promising theoretical approach for pediatric oncology.

A recently developed conceptual model of pediatric cancer-related QOL at the end of life is the Pediatric QOL at End-of-Life Model, which was derived from qualitative and quantitative research findings (Hinds, Oakes, Hicks, & Anghelescu, 2005). The model depicts the transition from curative to end-of-life care and reflects a dual focus on the QOL of the terminally ill child or adolescent and that of the family. The duality of focus is derived from research studies involving patient reports of wanting to be certain that the needs of family members who will survive will be addressed even while the patient is dying as well as after the patient has died (Hinds, Drew, et al., 2005; Hinds et al., 2001). The duality also is derived from parent reports that their quality of survival while their child is dying and after their child has died is influenced by the certainty that they made end-of-life decisions that were consonant with their personal, internal definition of being a "good parent" and that those decisions reflected their child's preferences (Hinds, Drew, et al., 2005; Hinds et al., 1997).

A second emerging conceptual model based on studies completed by a new three-setting collaboration to conduct end-of-life studies named "Relational Decision Making at End of Life in Pediatric Oncology" depicts the centrality of three interdependent perspectives in end-of-life decision making: those of the child or adolescent, the parent or guardian, and the healthcare provider. Relational decision making is depicted as being influenced by communication skills, competence, emotions, faith, and hope. The actual decision making influences symptom management and other treatment and care outcomes (Nuss, Hinds, & LaFond, 2005). The Pediatric QOL at End-of-Life Model and Nuss et al.'s model need to be explicated more fully at the conceptual level and then formally tested, including the use of quantitative techniques.

Advances in Measuring Pediatric Cancer-Related Quality of Life

At the time of the 1995 State-of-the-Knowledge Conference, perhaps the most apparent difference in the available QOL literature between adult and pediatric patients was the very small number of validated self-report instruments designed to measure one or more dimension of QOL in children and adolescents (Bradlyn et al., 1993; Goodwin, Boggs, & Graham-Pole, 1994; Phipps, Hinds, Channell, & Bell, 1994). As noted in a retrospective literature review of pediatric QOL studies, adult measures of QOL were administered with minimal alterations to pediatric patients or adult measures were used as a model for pediatric QOL instruments (Eiser & Morse, 2001). Since 1995, the number of self-report pediatric instruments has increased (Armstrong et al., 1999; Barr et al., 2000; Eiser, Kopel, Cool, & Grimer, 1999; Eiser & Morse; Varni, Katz, Seid, Quiggins, & Friedman-Bender, 1998; Varni, Katz, Seid, Quiggins, Friedman-Bender, et al., 1998) and now includes instruments tailored to measure QOL in specific pediatric and adolescent patients with cancer, such as bone marrow transplant recipients (Parsons, Barlow, Levy, Supran, & Kaplan, 1999; Seid et al., 1999), patients diagnosed with acute lymphoblastic leukemia (Pickard, Topfer, & Feeny, 2004), and survivors of childhood cancer (Bhatia et al., 2002, 2004; Shankar et al., 2005). Indeed, the increased number of pediatric cancer-related QOL instruments resulted in a recommendation for a moratorium in 1999 on developing new pediatric cancer QOL instruments (Feeny, Barr, Furlong, Hudson, & Mulhern, 1999; Guyatt, 1999). Instead, researchers were encouraged to test existing instruments. Examples of pediatric QOL instruments tested in three or more separate studies involving pediatric patients with cancer include the Pediatric QOL Inventory 4.0 (PedsQL 4.0) (Seid et al.; Varni, Katz, Seid, Quiggins, Friedman-Bender, et al.); Pediatric Cancer QOL Inventory 32 (PCQL-32) (Varni, Katz, Seid, Quiggins, & Friedman-Bender); Quality of Well-Being Scale (Bradlyn et al., 1993); Behavioral, Affective, and Somatic Experiences Scale (Phipps, Dunavant, Jayawardene, & Srivastava, 1999; Phipps et al., 1994); Perceived Illness Experiences (PIE) (Eiser et al.; Kiernan, Gormley, & MacLachlan, 2004); Health Utilities Index-Mark 3 (HUI-Mark 3) (Barr et al., 2000; Barr & Sala, 2005); and Child-Health Rating Inventories/Disease Impairment Inventories-Bone Marrow Transplant (Parsons et al.). The PedsQL 4.0, PCQL-32, and PIE also have been translated into languages other than English (Kiernan et al.).

In patient and parent reports of patient QOL, patients' reports tend to be more positive than parents' estimates (Levi & Drotar, 1999; Parsons et al., 1999). The differences in ratings were particularly common in the reports of internal experiences as reflected in the QOL domains of emotion and cognition. Whether the differences in ratings persist over the course of therapy and whether the differences are of a predictable direction or size across time have not yet been determined.

In their report, Sung et al. (2004) suggested the possibility that discrepancies in patient and parent QOL ratings could be related to the methods used to solicit the ratings. The differences over time and methods need to be considered in future research. Regardless of the patient and parent discrepancies in ratings, researchers well steeped in the measurement of pediatric cancer-related QOL have recommended solicit-

ing QOL ratings from children as young as age five (Varni, Katz, Seid, Quiggins, Friedman-Bender, et al., 1998) and age seven or eight (Parsons et al., 1999). One caution is that the items developed specifically for and tested in children and adolescents who are in active treatment for cancer or who are survivors of childhood cancer may not reflect the relational aspects of patients' QOL at the end of life. The validity and feasibility of using the available pediatric cancer-related QOL instruments during terminal care have not been established and remain important research and care priorities (Bradlyn, 2004; Bradlyn, Varni, & Hinds, 2003). Careful measurement of QOL in pediatric oncology requires that data be collected at regular intervals, from the time of diagnosis throughout survivorship or end of life, and that the QOL data be collected in concert with clinical indicators so that a clinical context is included in the interpretation of the data.

In some studies, healthcare professionals have provided proxy reports of the QOL of pediatric patients with cancer. One challenge to the proxy role for professionals is not being able to respond completely to all items on the QOL instrument because some items relate to internal patient experiences or to patients' functional abilities that occur outside of the clinical setting, which are not observable by staff. A second challenge to the staff proxy role occurs when the items of selected QOL instruments only measure the status of nonacutely ill pediatric patients with cancer or when the items cannot distinguish the effects of preexisting conditions from the effects of current disease or treatment (Cox et al., 2005). If staff members are to provide the estimates of a patient's QOL, the QOL items need to be selected carefully to reflect aspects of patient behavior, emotions, and expressions that are observable in the regular practice of a pediatric oncology nurse. A selective measurement approach using staff as proxy will decrease the likelihood of missing data secondary to staff not being able to observe what the focus of the item(s) is and will yield findings that can be translated more readily into direct nursing care. In addition, statistical techniques, described by Naeim, Keeler, and Mangione (2005), to address missing items in QOL assessments, particularly those that occur with the HUI-Mark 3, may be of some assistance with this troubling issue.

Researchers should use theories that are grounded in the experiences of children and adolescents to systematically guide decisions about which data to collect and how to interpret the data. As part of a theory-driven approach, an expanded measurement of pediatric cancer-related QOL should include the role that positive health concepts, especially the role of spiritual perspective and connectedness with healthcare providers, has on patient and family QOL. The same theory-driven approach to measurement applies to the delivery of interventions. Because pediatric cancer-related QOL is multidimensional and dynamic over time, priority needs to be given to intervention delivery methods that can be matched to patient characteristics and preferences as well as treatment characteristics. For example, expressive therapies, such as music, seem to be intervention delivery methods that can be matched to the age and preferences of a child or adolescent.

Advances in Methods Used to Collect Quality-of-Life Data

Electronic devices, such as laptop and desktop computers and touch pads, are being used increasingly to collect pediatric

cancer-related QOL data. For example, in a randomized pilot study of a six-session music video intervention for adolescents and young adults undergoing stem cell transplant, pre- and post-transplant measures were collected using a laptop. The participants had no difficulty using the laptop and completed the measures more quickly than another group of participants, similar in age, who completed the same measures using pen-and-paper methods (30–40 minutes versus 60–75 minutes per participant) (Haase, Burns, & Robb, 2004).

Another potential method for pediatric QOL data collection is the World Wide Web. Web-based research is emerging as a useful tool for (a) recruitment, whereby information can be obtained from individuals who are not easily accessible in sufficient numbers to conduct on-site or even limited-site studies (Lakeman, 1997; Satia, Galanko, & Rimer, 2005), (b) support groups and interaction with patients with cancer (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Hoybye, Johansen, & Tjornhoj-Thomsen, 2005; Klemm, Reppert, & Visich, 1998; Lieberman et al., 2003; Smith, 1998; Winzelberg et al., 2003), (c) quantitative surveys or questionnaire-based research (Ellett, Bleah, & Parris, 2004; Janson & Wjst, 2004; Kypri, Gallagher, & Cashell-Smith, 2004; Levine, 2004; Sadeh, 2004), and (d) collecting data from adolescents and young adults because they often are high users of Web-based technology (Borzekowski & Rickert, 2001). Evidence has shown that adolescents and young adults with cancer use chat rooms and other discussion forums to describe their experiences on cancer-specific Web sites targeted to their age groups (e.g., www.teenslivingwithcancer.org, www.planetcancer.org). Discussion forums and bulletin boards have not been used for research purposes related to pediatric cancer QOL but may be valuable future research tools.

Potential Clinical Applications of Quality-of-Life Scores

Electronic measurement of pediatric cancer-related QOL will yield a profile of scores that could help patients and families identify the strengths that will aid them in their efforts to cope with cancer and its treatment. The theoretically based profile of QOL items could be completed throughout treatment, and survivorship and scores from each time point could be reviewed with patients and families. For example, in a pilot study, this article's third and fourth authors administered the ARM measures to five adolescents at the time of diagnosis. The data were shared with each adolescent, his or her family, and the oncology team in a two-page summary that also included comparison scores by age and gender for each measure. The adolescents and families reviewed their scores and the pertinent comparison information and used it to affirm their strengths in coping with the cancer experience. The research team members used the scores and comparison information to expand their understanding of the family by specifically seeking information when the scores were discrepant from their initial clinical impressions. Having patients and parents complete the measures over the course of treatment and clinical situations also would provide information on potential differences and similarities in patient and parent perspectives. Clinical use of the scores over time could serve as a catalyst for more effective communication among adolescents, parents, and healthcare professionals.

Clinical Context Assists in Interpreting Quality-of-Life Scores

A score for pediatric cancer-related QOL is important but insufficient. Scores need to be considered within the context of patients' clinical status and overall situation. Two examples illustrate this (Haase, 2005). In a pilot study of a coping intervention, a Hispanic mother and 15-year-old adolescent with sarcoma had scores indicating excellent family communication, but the mother was reluctant to allow staff to discuss the diagnosis of cancer or treatment options with her daughter. The oncology team then wondered if the family communication scores were a valid reflection of the parent-adolescent communication. When this discrepancy was discussed with the mother, she indicated that her hesitation about staff discussing the diagnosis and treatment with her daughter was related to timing; she wanted her daughter to experience the already scheduled *Quinceanera*, a debutante ball of Hispanic tradition, before such treatment discussions occurred. The discrepancy between the communication scores and the staff's clinical impressions led to the additional information being elicited. The initial staff perceptions of family communication were altered on the basis of additional important information and helped the staff to address the mother's actual concerns.

In the second example, the importance of context in interpreting QOL data is demonstrated. Coping strategies frequently are measured as a predictor of QOL; however, the strategies are evaluated infrequently for their relevance to children and adolescents in the context of cancer. When items are not applicable in a specific context, their inclusion in a scale decreases the usefulness of the scale's ability to predict outcomes such as QOL. Adolescent patients indicated that certain coping strategies reflected in the items of the Jalowiec Coping Scale either were ambiguous in meaning because of the cancer context (e.g., "daydreaming" is considered a defensive avoidance strategy, but patients with cancer may be taught guided imagery as a positive coping strategy) or were not real options for coping in the context of cancer (e.g., "tried to ignore the situation" is not an option at the time of diagnosis of cancer) (Haase, 2005).

Application of Advances to the Care of Pediatric Patients With Cancer

The incorporation of QOL into direct patient care is beginning to emerge. For example, a care model based on the nursing role in influencing patient QOL in positive ways is the application of the American Association of Critical-Care Nurses ([AACN], 2005) Synergy Model for Patient Care by the nurses at Clarian Health Partners, a multihospital system in Indianapolis, IN ("Multihospital System Adapts," 2003). The primary premise of the model is that positive patient outcomes occur when patient characteristics and nurse competencies are aligned mutually with one another. Eight patient characteristics are evaluated by nurses: (a) participation in decision making: the extent to which patient and family members engage in making decisions about treatment, (b) participation in care: the extent to which patient and family members actively are involved in aspects of care, (c) stability: the ability to maintain a steady state of equilibrium, (d) complexity: the entanglement of two or more systems, (e) resiliency: the ability to return to the original state of being before the insult or illness occurred,

(f) vulnerability: susceptibility to internal or external stressors that may have an adverse effect on patient outcomes, (g) resource availability: the extent of resources that are available to the patient and family members, and (h) predictability: an identifiable characteristic that allows an individual to expect a certain path of an event or illness (AACN). Nurses then apply one or more of the eight nursing competencies to respond to the needs of their patients to enhance outcomes. The nursing competencies include clinical judgment, caring practices, advocacy, collaboration, response to diversity, facilitator of learning, clinical inquiry, and systems thinking. The primary goal is to restore the patient to an optimal level of wellness as defined by the patient.

Curricular Recommendations for Pediatric Cancer-Related Quality of Life

A curricular plan designed to assist students or staff in developing nursing skills for assessing and enhancing QOL is recommended. First, QOL should be taught from a theoretical perspective, emphasizing examination of multiple factors that influence QOL that may be amenable to interventions initiated by healthcare providers. Particular benefit for students could result from a theory-based curriculum that facilitates consideration of positive health perspectives—assessing individual patient and family strengths and using the assessments as the basis for QOL interventions. Because illness-related factors influence QOL, curricula should emphasize symptom assessment and management and interdisciplinary collaboration to provide care that enhances pediatric cancer-related QOL. Finally, a formal, structured curriculum component on the clinical application of pediatric cancer-related QOL is recommended.

Conclusions

Remarkable advances have occurred since the 1995 Oncology Nursing Society's State-of-the-Knowledge Conference on QOL and include a definition of pediatric cancer-related QOL from the pediatric patient, thus giving voice to the child's and adolescent's own cancer experiences. Model development and testing have progressed across distinct points of care, although significant conceptual and empirical work remains for pediatric cancer-related QOL at the end of life. Measurement of cancer-related QOL in children and adolescents similarly has advanced and includes generic and population-specific instruments, some of which also are available in multiple languages. The focus now is on linking data collection to clinical events to provide a clinical context for interpretation of pediatric cancer-related QOL. Clinical application of QOL models to care settings or the use of QOL scores in clinical situations just now is occurring, requiring more intense attention and evaluation in the future. The advances allow the true assessment of pediatric cancer-related QOL at different points of care and the testing of care interventions to improve or prevent decreases in the QOL of pediatric patients with cancer. Translation of pediatric QOL models and scores into clinical practice is in its early stages, but a promising recognition of the importance of this concept for patients, families, and healthcare professionals is certain to continue this trend.

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