

Children's Experiences of Cancer Care: A Systematic Review and Thematic Synthesis of Qualitative Studies

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PROBLEM IDENTIFICATION: Improvements in pediatric cancer survival have increased interest in the experiences of children undergoing treatment; however, no review of the qualitative literature describing these experiences has been conducted.

LITERATURE SEARCH: Databases were searched from January 2000 to January 2016 for qualitative studies describing the experience of children with cancer aged 18 years or younger.

DATA EVALUATION: Two reviewers assessed abstracts for relevance and rated reporting comprehensiveness. Participant quotations and descriptions of participants' comments and behaviors were coded. Coded data were pooled to provide a thematic synthesis.

SYNTHESIS: 51 studies were included. Five themes were identified: suffering because of cancer, fluctuating realities, coping strategies, new roles and responsibilities of the child, and practical resources to enable managing cancer. Children articulated physical, emotional, and social challenges and made suggestions to improve their quality of life during therapy.

IMPLICATIONS FOR RESEARCH: Results provide data related to the experience of children with cancer that can inform practice changes and research activities aimed at enhancing quality of life.

KEYWORDS cancer; pediatrics; qualitative research; systematic review; thematic synthesis

ONF, 45(4), 527-544.

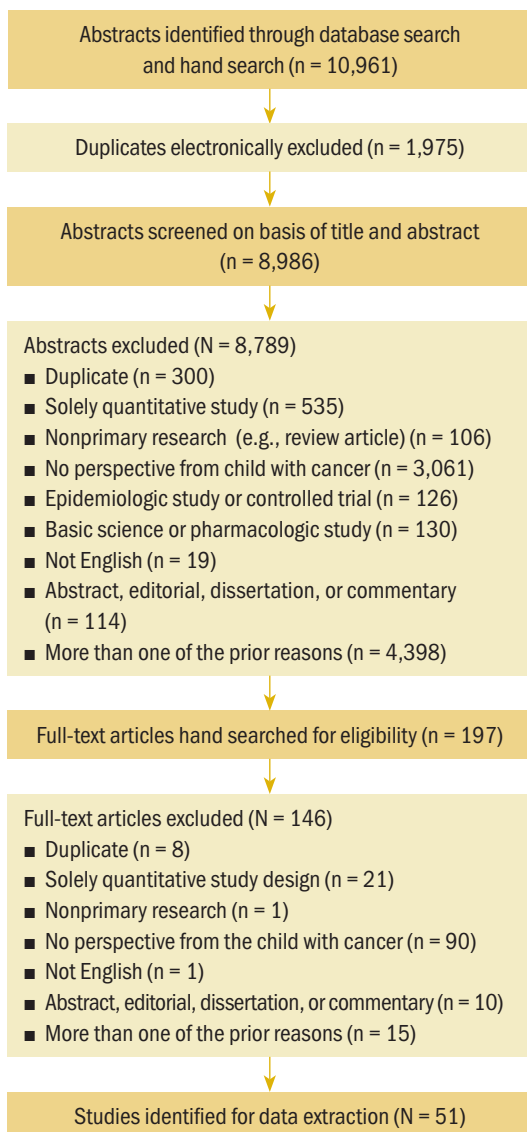
DOI 10.1188/18.ONF.527-544

Cancer is a leading cause of disease-related death in children and adolescents globally (Magrath et al., 2013; Siegel et al., 2014). However, the long-term survival rate of children with cancer is increasing, and the five-year survival rates across all cancer types in high-income countries exceed 80% (American Cancer Society, 2016; Hudson, Link, & Simone, 2014). Still, the burden of the disease and the intensive nature of cancer therapies are associated with acute toxicities and chronic health conditions that are often life-threatening (Hudson et al., 2013). During cancer treatment, children and adolescents with cancer experience a myriad of physical (e.g., pain, nausea, fatigue, hair loss) and psychosocial (e.g., stress, anxiety, depression, isolation) symptoms related to the disease, invasive procedures, and/or chemotherapy and radiation (Baggott et al., 2010; Dupuis et al., 2010; French et al., 2013; Zhukovsky et al., 2015). Children and adolescents with cancer are challenged to adhere to complex and often time-consuming treatment regimens, manage adverse effects, plan for the future (including transition to adult care or aftercare), and maintain a positive outlook (Zebrack & Isaacson, 2012).

Examination of the impact of cancer and its treatment from the patient's perspective has been advocated for at national levels to complement traditional, medically focused outcomes and to provide a comprehensive picture of treatment effectiveness (Dueck et al., 2015; Reeve et al., 2013; Thornton, 2008). Qualitative research can provide detailed insight into the beliefs and experiences of individuals with cancer, including children, which can be used to shape clinical care and research (Sigurdson & Woodgate, 2015). A body of qualitative literature has explored the experiences of children with

cancer undergoing treatment from the perspective of the child; however, a critical synthesis of these data across patient groups and healthcare contexts, particularly those data related to the experience of children with cancer of different ages and developmental stages, does not exist. The aim of this article is to systematically review, appraise, and synthesize the evidence describing the life experiences (physical, emotional, cognitive, and social) of children receiving cancer treatment to inform clinical practice according to the wants and needs of children to ultimately improve quality of life.

FIGURE 1. Flow Diagram of Study Screening Process



Methods

The ENTREQ (enhancing transparency in reporting the synthesis of qualitative research) framework (Tong, Flemming, McInnes, Oliver, & Craig, 2012) guided reporting in this review.

Eligibility Criteria

Primary English-language qualitative or mixed-method studies of children and adolescents aged 18 years or younger receiving care (active or end-of-life) for any type of cancer in pediatric- or adolescent-specific facilities and who reported their own life experiences during cancer treatment were included. To obtain data from the patients and to minimize recall bias in reporting, the authors excluded data from proxy reporters (i.e., parents or healthcare providers) and childhood cancer survivors.

Data Sources and Screening

The authors electronically searched MEDLINE®, EMBASE, CINAHL®, and PsycINFO. To provide a synthesis relevant to modern cancer care practices, they restricted the search to articles published from January 2000 to January 2016. In addition, to capture the greatest possible number of qualitative studies, the authors developed a broad search strategy in consultation with and executed by a pediatric hospital librarian familiar with the content area. Details of search terms may be requested from the authors. Two authors independently screened all titles and abstracts for relevance. Disagreements were resolved through third-party arbitration. Potentially relevant full-text articles were similarly assessed for eligibility.

Study Appraisal and Data Analysis

To enable readers to evaluate the trustworthiness and transferability of each study's findings, the authors assessed the transparency of reporting for all studies using an adapted version of the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong, Sainsbury, & Craig, 2007).

The tool was adapted by removing three items related to the summary findings and interpretations of authors of primary studies and adding an assessment of result triangulation and the range and depth of insight into participant perspectives. This adaptation has been used to assess comprehensiveness in systematic reviews of pediatric qualitative research (Jamieson et al., 2014). Two authors independently assessed reporting by all studies. No studies were excluded based on comprehensiveness of reporting.

TABLE 1. Study Characteristics (N = 51)

Study and Location	Sample, Condition, and Time Since Diagnosis	Data Collection, Methodology, and Analysis	Explored Cancer Experiences
Adejoh et al., 2013 (Nigeria)	1 patient aged 13–18 years with leukemia	Interview, thematic analysis	Cognitive and psychosocial effects of treatment
Al Omari & Wynaden, 2014 (Jordan)	14 patients (9 male, 5 female) aged 13–17 years (\bar{X} = 14.9 years) with leukemia (n = 6), Hodgkin lymphoma (n = 5), and non-Hodgkin lymphoma (n = 3); time since diagnosis less than 3 months	Semistructured interview, interpretative phenomenology, thematic analysis	Hematologic malignancy
Ångström-Brännström & Norberg, 2014 (Sweden)	9 patients (5 male, 4 female) aged 3–9 years with leukemia (n = 5) and a solid tumor (n = 4)	Interview using art to elicit thoughts and emotions, content analysis	Comfort
Barrera et al., 2005 (Canada)	9 patients (5 male, 4 female) aged 7–15 years with a brain tumor (n = 5), neuroblastoma (n = 3), and ALL (n = 1); time since diagnosis 2–93 months (\bar{X} = 38.9 months)	Semistructured interview, content analysis	Health-related quality of life and participation in phase 1 trials
Barry et al., 2010 (Australia)	11 patients aged 6–13 years	Open-ended interview, grounded theory, thematic analysis	Music therapy on distress and coping during radiation therapy
Björk et al., 2005 (Sweden)	5 patients aged 9–11 years (median = 11 years) with leukemia (n = 3), brain tumor (n = 1), and solid tumor (n = 1); time since diagnosis less than 1 month	Unstructured interview, hermeneutical phenomenology, thematic analysis	Cancer diagnosis
Björk et al., 2006 (Sweden)	12 patients (6 male, 6 female) aged 7–78 months (median = 20.5 months) with leukemia (n = 6), brain tumor (n = 3), and solid tumor (n = 3)	Unstructured observation, content analysis	Needs during hospitalization
Bossert et al., 2002 (United States)	3 patients (2 male, 1 female) aged 6–15 years (\bar{X} = 10 years) with ALL (n = 2) and AML (n = 1)	Structured interview	Pain management strategies
Corsano et al., 2015 (Italy)	27 patients (12 male, 15 female) aged 6–15 years with a hematologic malignancy (n = 15), solid tumor (n = 8), and blood disorder (n = 4)	Structured interview, thematic analysis	Healthcare providers
Coyne et al., 2014 (Ireland)	20 patients (11 male, 9 female) aged 7–16 years with leukemia (n = 6), sarcoma (n = 5), CNS tumor (n = 4), lymphoma (n = 4), and kidney tumor (n = 1); time since diagnosis 1–12 months	Open-ended interview, constructivist grounded theory, thematic analysis	Participation in information sharing
Darcy et al., 2014 (Sweden)	9 patients aged 2–5 years; time since diagnosis 9 weeks or less	Open-ended interview, content analysis	Health and everyday life
de Chico Cicogna et al., 2010 (Brazil)	10 patients aged 8–18 years	Semistructured interview, thematic analysis	Chemotherapy treatment
Diorio et al., 2012 (Canada)	21 patients (11 male, 10 female) aged 12–17 years (median = 12 years) with lymphoma (n = 7), leukemia or another hematologic malignancy (n = 5), solid tumor (n = 5), and other cancers (n = 4)	“Think aloud” and interview, thematic analysis	Infection prophylaxis
Docherty et al., 2006 (United States)	1 female patient aged 16 years with Hodgkin lymphoma; time since diagnosis 3 months	Interview, content analysis	Symptom distress during chemotherapy treatment
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TABLE 1. Study Characteristics (N = 51) (Continued)

Study and Location	Sample, Condition, and Time Since Diagnosis	Data Collection, Methodology, and Analysis	Explored Cancer Experiences
Flavelle, 2011 (Canada)	1 male patient with osteosarcoma aged 15 years; time since diagnosis 1 year	Participant diary, phenomenology	Living with and dying of cancer
Gibson et al., 2012 (United Kingdom)	13 patients (5 male, 8 female) aged 4–12 years with relapsed ALL (n = 2), non-Hodgkin lymphoma (n = 2), Wilms tumor (n = 2), brain tumor (n = 2), ALL (n = 1), Hodgkin lymphoma (n = 1), relapsed Wilms tumor (n = 1), relapsed AML (n = 1), and primitive neuroectodermal tumor (n = 1); time since diagnosis more than 1 month	Interview using art and diaries to elicit thoughts and emotions, thematic analysis	Food intake and nutritional management
Griffiths et al., 2011 (Australia)	9 patients aged 8–16 years (\bar{X} = 11.9 years) with leukemia (n = 2), Hodgkin lymphoma (n = 2), medulloblastoma (n = 2), Langerhans cell histiocytosis (n = 1), non-Hodgkin lymphoma (n = 1), and nonmalignant brain tumor (n = 1); time since diagnosis less than 3 years	Semistructured interview, phenomenology, thematic analysis	Child vulnerabilities and life-threatening component of cancer
Hildenbrand et al., 2011 (United States)	15 patients (8 male, 7 female) aged 6–12 years (\bar{X} = 8.8 years) with leukemia (n = 4), brain tumor (n = 4), lymphoma (n = 3), neuroblastoma (n = 2), and sarcoma (n = 2); time since diagnosis 1 week to 3.5 years	Semistructured interview, thematic analysis	Cancer-related stressors and coping
Hildenbrand et al., 2014 (United States)	15 patients aged 6–12 years (\bar{X} = 9.5 years) with ALL (n = 5), brain tumor (n = 2), lymphoma (n = 2), osteosarcoma (n = 2), and other cancers (n = 4); time since diagnosis 1 day to 27 weeks (\bar{X} = 6.8 weeks)	Semistructured interview, thematic analysis	Cancer-related stressors and coping
Ishibashi et al., 2010 (Japan)	7 patients (1 male, 6 female) aged 11–18 years with AML (n = 4), ALL (n = 2), and non-Hodgkin lymphoma (n = 1)	Semistructured interview, case study, content analysis	Development of resilience
Larouche & Chin-Peuckert, 2006 (Canada)	5 patients (3 male, 2 female) aged 14–17 years (\bar{X} = 15.6 years) with RMS (n = 1), Hodgkin lymphoma (n = 1), leukemia (n = 1), osteosarcoma (n = 1), and Ewing sarcoma (n = 1); time since diagnosis 3–12 months	Semistructured interview, case study, thematic analysis	Body image and its perceived impact on daily life
Li et al., 2010 (China)	98 patients (51 male, 47 female) aged 7–15 years with leukemia (n = 36), lymphoma (n = 23), brain tumor (n = 15), germ cell tumor (n = 13), osteosarcoma (n = 11); time since diagnosis less than 6 months	Semistructured interview, content analysis	Disease impact on physical, emotional, and psychosocial well-being
Li et al., 2011 (China)	88 patients (47 male, 41 female) aged 9–16 years with leukemia (n = 39), lymphoma (n = 26), brain tumor (n = 9), germ cell tumor (n = 8), and osteosarcoma (n = 6); mean time since diagnosis 5.8 months	Semistructured interview, content analysis	Coping strategies during hospitalization
Lurie & Kaufman, 2001 (United States)	3 patients (1 male, 2 female) aged 6–7.5 years (\bar{X} = 6.8 years) with ALL	Interview	Cognitive, psychological, and social adjustment to school reintegration
Mancini et al., 2012 (France)	43 patients (21 male, 22 female) aged 3–17 years with ALL	Semistructured interview	Adherence to oral chemotherapy and factors associated with nonadherence
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TABLE 1. Study Characteristics (N = 51) (Continued)

Study and Location	Sample, Condition, and Time Since Diagnosis	Data Collection, Methodology, and Analysis	Explored Cancer Experiences
Manookian et al., 2014 (Iran)	6 patients (3 male, 3 female) aged 6–17 years (\bar{X} = 11.3 years) with ALL (n = 2), thalassemia (n = 2), chronic myeloid leukemia (n = 1), and Hodgkin lymphoma (n = 1)	Semistructured interview, interpretive phenomenology, thematic analysis	Hematopoietic stem cell transplantation
McGrath et al., 2004 (Australia)	3 patients (1 male, 2 female) aged 12–15 years (\bar{X} = 13.7 years) with AML; time since diagnosis 2–3 months	Interview, descriptive phenomenology, thematic analysis	Cancer treatment
Melo Lde & do Valle, 2010 (Brazil)	7 patients aged 3–9 years	Interview using toys to elicit thoughts and emotions, phenomenology	Ambulatory cancer treatment
Momani et al., 2015 (United States)	150 patients (93 male, 57 female) aged 8–18 years with ALL	Structured interview, content analysis	Health-related quality of life
Nguyen et al., 2010 (Vietnam)	40 patients (25 male, 15 female) aged 7–12 years with leukemia	Semistructured interview, content analysis	Music therapy on pain and anxiety during lumbar puncture
Nilsson et al., 2009 (Sweden)	42 patients (25 male, 17 female) aged 5–18 years (median = 11 years) with a CNS tumor (n = 12), leukemia (n = 10), other solid tumor (n = 9), hematologic disease (n = 6), and lymphoma (n = 5)	Semistructured interview, methodologic orientation, content analysis	Virtual reality therapy on pain and distress during needle procedures
O'Callaghan et al., 2011 (Australia)	26 patients (19 boys, 7 girls) aged 4–8 years (median = 5.7 years) with leukemia (n = 18), neuronal malignancy (n = 6), non-neuronal solid tumor (n = 3), and lymphoma (n = 2)	Semistructured interview, constructivist grounded theory	Music therapy during treatment
Rindstedt, 2004 (Sweden)	5 patients (1 male, 4 female) aged 2–16 years (\bar{X} = 7.6 years) with ALL	Observation, video ethnography, conversation analytical approaches and linguistic anthropology	Fantasy, play, and coping
Rollins, 2005 (United Kingdom and United States)	22 patients (13 male, 9 female) aged 7–18 years with ALL (n = 11), Hodgkin lymphoma (n = 4), brain tumor (n = 2), AML (n = 2), Wilms tumor (n = 1), osteogenic sarcoma (n = 1), and orbital RMS (n = 1)	Semistructured interviews, drawings, and observations were sources of data for analysis, grounded theory	Child stressors, coping mechanisms, and how drawing can enhance communication
Searle et al., 2003 (United States)	10 patients (5 male, 5 female) aged 13–18 years (\bar{X} = 15.2 years) with osteosarcoma (n = 3), ALL (n = 2), nasopharyngeal carcinoma (n = 1), squamous cell carcinoma (n = 1), brain tumor (n = 1), melanoma blue cell nevus (n = 1), and AML (n = 1); time since diagnosis 1–3 years	Interview, ethnographic, case study, thematic analysis	Educational experiences while enrolled in hospital, home, or community school
Skolin et al., 2006 (Sweden)	22 patients (16 male, 6 female) aged 2–17 years (median = 8 years) with leukemia (n = 9), solid tumor (n = 6), lymphoma (n = 5), and CNS tumor (n = 2); time since diagnosis 1–12 months (median = 4 months)	Semistructured interview	Food intake and nutritional management
Soanes et al., 2009 (United Kingdom)	10 patients (5 male, 5 female) aged 4–13 years with medulloblastoma (n = 3), astrocytoma (n = 2), glioblastoma multiforme (n = 2), primitive neuroectodermal tumor (n = 2), and high-grade glioma (n = 1)	Semistructured interview and art to elicit thoughts and emotions, thematic analysis	Cancer treatment
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TABLE 1. Study Characteristics (N = 51) (Continued)

Study and Location	Sample, Condition, and Time Since Diagnosis	Data Collection, Methodology, and Analysis	Explored Cancer Experiences
Sposito et al., 2015 (Brazil)	10 patients (5 boys, 5 girls) aged 7–12 years (\bar{X} = 9.8 years) with osteosarcoma (n = 3), ALL (n = 2), non-Hodgkin lymphoma (n = 2), Ewing sarcoma (n = 1), RMS (n = 1), and medulloblastoma (n = 1); time since diagnosis 4–33 months (\bar{X} = 11.4 months)	Semistructured interview, thematic content analysis	Coping strategies
Stegenga & Ward-Smith, 2008 (United States)	3 patients (1 male, 2 female) aged 13–15 years (\bar{X} = 13.6 years); time since diagnosis 4–6 months	Semistructured interview, phenomenology, content analysis	Treatment decision making
Stegenga & Ward-Smith, 2009 (United States)	10 patients (1 male, 9 female) aged 13–17 years (\bar{X} = 14.9 years); time since diagnosis 4–6 months	Semistructured interview, phenomenology	Cancer diagnosis
Stevens et al., 2006 (Canada)	14 patients (9 male, 5 female) with a mean age of 12 years with ALL; time since diagnosis less than 1 year	Semistructured interview, content analysis	Home chemotherapy program
Stewart, 2003 (United States)	11 patients (6 male, 5 female) aged 9–12 years with various malignancies (n = 10) and aplastic anemia (n = 1)	Semistructured interview, grounded theory, thematic analysis	Uncertainty
Stinson, Jibb, et al., 2015 (Canada)	20 patients (9 male, 11 female) aged 12–17 years (\bar{X} = 15 years) with ALL (n = 4), osteosarcoma (n = 3), Ewing sarcoma (n = 2), non-Hodgkin lymphoma (n = 2), other solid tumors (n = 2), RMS (n = 2), acute promyelocytic leukemia (n = 1), brain tumor (n = 1), Hodgkin lymphoma (n = 1), post-transplantation lymphoproliferative disease (n = 1), and synovial sarcoma (n = 1); time since diagnosis 0.2–5.4 years (\bar{X} = 1.8 years)	Semistructured interview, phenomenology, content analysis	Romantic relationships, sexual relationships, and fertility
Tamannai et al., 2015 (Cameroon)	3 patients (1 male, 2 female) aged 9–14 years (\bar{X} = 11 years) with Burkitt lymphoma	Semistructured interview, thematic analysis	Palliative care in rural setting
Weaver et al., 2015 (United States)	40 patients (24 male, 16 female) aged 12–18 years (\bar{X} = 15.5 years) with leukemia or lymphoma (n = 24), solid tumor (n = 13), and CNS tumor (n = 3); time since diagnosis 2 weeks to 6 months (\bar{X} = 2.9 months)	Open-ended interview, grounded theory, semantic content analysis	Medical decision-making preferences
Williamson et al., 2010 (United Kingdom)	22 patients (2 male, 20 female) aged 13–18 years with ALL (n = 4) and other cancers (n = 18)	Semistructured interview or written account, case study, template analysis	Appearance change
Wilson et al., 2011 (United States)	3 patients (2 male, 1 female) aged 6–17 years (\bar{X} = 11.7 years) with ALL (n = 1), AML (n = 1), and RMS (n = 1); time since diagnosis 30 days to 4 years	Interview, case study	Cancer treatment and helpful interventions
Woodgate et al., 2014 (Canada)	13 patients aged 8–17 years (\bar{X} = 11 years) with leukemia or lymphoma (n = 7), brain tumor (n = 4), and osteosarcoma (n = 2)	Diary and interview, interpretive phenomenology, content analysis	Challenges faced
Wu et al., 2010 (China)	14 patients (6 male, 8 female) aged 7–18 years (\bar{X} = 10.9 years), 11 with ALL and 3 with AML; time since diagnosis 2 weeks to 2 years	Focus group interview, phenomenology content analysis	Fatigue
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TABLE 1. Study Characteristics (N = 51) (Continued)

Study and Location	Sample, Condition, and Time Since Diagnosis	Data Collection, Methodology, and Analysis	Explored Cancer Experiences
Yeh, 2001 (Taiwan)	34 patients (23 male, 11 female) aged 4–17 years (\bar{X} = 11.4 years) with ALL (n = 12), lymphoma (n = 8), other leukemias (n = 7), AML (n = 3), and other cancers (n = 4)	Semistructured interview, focus group, observation and medical chart notes, grounded theory, content analysis	Adaptation
Yeh, 2002 (Taiwan)	16 patients (9 male, 7 female) aged 13–17 years (\bar{X} = 14.8 years) with leukemia (n = 10), lymphoma (n = 3), and other cancers (n = 3)	Semistructured interview, grounded theory, content analysis	Cancer treatment
ALL—acute lymphoblastic leukemia; AML—acute myeloid leukemia; CNS—central nervous system; RMS—rhabdomyosarcoma			

Study characteristics were extracted into standardized tables. Thematic synthesis methods that have been previously described (Thomas & Harden, 2008) and used successfully in syntheses of qualitative pediatric health research (Jamieson et al., 2014; Nelson et al., 2015) were used. A copy of each identified study was uploaded into NVivo 10 software. Two authors (both pediatric oncology nurses) independently conducted line-by-line coding of the results section of each study, specifically coding direct quotations and descriptions of participants' comments and behaviors using an inductive approach. As data were coded, a bank of codes was developed and applied across all studies. Coding choices were discussed between authors frequently, and discrepancies were resolved using group discussion with a third author. Codes were collapsed, if appropriate, and grouped into themes. Themes produced from the data and relationships among themes were discussed as a group.

Results

Study Characteristics

The search strategy revealed 10,961 abstracts; 51 unique articles met inclusion criteria (see Figure 1). A total of 1,014 children and adolescents aged 2–18 years from 16 countries contributed data to this review. Children had diagnoses from each of the major childhood cancer groups (i.e., hematologic, solid tumor, or central nervous system tumor). The number of children per study ranged from 1–150 (\bar{X} = 20, SD = 26). Studies used open-ended, semistructured, or structured interviews to collect data from children.

The characteristics of individual studies are shown in Table 1. Included studies reported, on average, 14 (SD = 4, range = 7–31) of the adapted 31 COREQ

items. Specific COREQ items that were reported can be requested from the primary author. All studies described the participant sample. Forty-six studies (90%) provided raw data in the form of participant quotations or artwork, enhancing trustworthiness of results. Other elements enabling the assessment of trustworthiness were not frequently reported, including member checks, which were conducted in 9 studies (18%).

Synthesis

Thematic synthesis of coded data resulted in five distinct themes describing the experiences of children during cancer therapy:

- Suffering because of cancer
- Fluctuating realities
- Coping strategies
- New roles and responsibilities of the child
- Practical resources to enable managing cancer

Each theme and any associated subthemes are described in this article, with representative quotations shown in Figures 2–6.

Suffering Because of Cancer

The most prevalently articulated topic by children with cancer, which transcended age at interview, diagnosis, or year of study publication, was the suffering they experienced because of the disease. In particular, younger children stressed the physical suffering with cancer-related symptoms and pain-related invasive procedures, whereas older children highlighted the emotional and social burden of the disease.

The suffering experienced by children was noted as fundamental physical, social, and emotional differences they observed in themselves after being

FIGURE 2. Exemplary Quotations Providing Evidence for Suffering Because of Cancer

Physical, emotional, and social burden

- “[Because of fatigue, I] don’t know if I want Emmie here. Sure, I love hanging out with her and just chillin’, but I don’t want her to see me like this either. I don’t wanna get really mad at her ‘cause I’m in pain or don’t wanna sleep the whole time she visits.” (15 years old) (Flavelle, 2011, p. 31)
- “I’m still scared [crying]. I’m afraid to be injected. It’s very painful. When the doctor came in, my heart seemed to act in chaos until he left [crying].” (Nguyen et al., 2010, p. 151)
- “I always played with my best friend before; now we never play.” (4 years old) (Darcy et al., 2014, p. 452)

diagnosed with cancer. Emotional changes included anger, sadness, and anxiety, and social shifts included negative changes in conceptions of close relationships, particularly with friends. Participants also articulated struggles with pain, nausea, and fatigue, which diminished quality of life, caused resentment toward therapy, and affected relationships with others. Younger children focused more often on the physical symptoms of cancer. Young children feared these symptoms, particularly pain caused by skin-breaking procedures, and expressed a related fear of their healthcare providers. Adolescents recounted their experiences with the physical burden of cancer and its therapy, stating that losing their hair (Larouche & Chin-Peuckert, 2006) and being “really skinny” (de Chico Cicogna, Nascimento, & de Lima, 2010, p. 869) lessened their confidence and limited social interaction. Adolescents also were more negatively affected by the emotional and social burdens of cancer treatment, including its effects on peer relationships.

Fluctuating Realities

Children and adolescents also described existing in a sense of fluctuating realities. To this end, participants described cancer treatment as a turbulent experience in which quality of life, their will to cope with treatment, and their sense of optimism related to the future continually varied.

Across participant age groups and diagnoses, children and adolescents described themselves as living in juxtaposition between celebrating small victories and appreciating the life-threatening nature of cancer. Participants desired to “make life what it’s supposed to be” (Barrera, D’Agostino, Gammon, Spencer, & Baruchel, 2005, p. 194) regardless of cancer-related

limitations. In these cases, participants spoke of relationships with family and friends, positive care experiences from clinicians, and fun activities as being high points during therapy. Still, they shared that these high points were interrupted by cancer low points, such as negative symptoms and feelings of isolation. One young child described an inability to consistently maintain emotional high points: “Mommy usually comforts me when I’m sad. Then I stop crying, but I don’t get happy. But it feels better anyway” (Ångström-Brännström & Norberg, 2014, p. 140).

Participants also described periods of exasperation with symptoms and felt they “might not be up to the challenge” (Docherty, Sandelowski, & Preisser, 2006, p. 305) of fighting the actual disease. In these cases, the burden of distressing symptoms and procedures often outweighed the perceived benefits of undergoing treatment. Younger children in particular frequently discussed their distaste for diagnostic tests and invasive procedures and did not appreciate that they were needed to treat their cancer.

Many participants described a capacity to maintain a hopeful outlook with respect to the effect of therapy while also mentally preparing for negative health outcomes. For instance, related to phase 1 therapeutic studies, one adolescent stated, “I had been hearing things about people with brain tumors that actually got cured by it [phase 1 study drug]” (Barrera et al., 2005, p. 194).

Coping Strategies

Analyses revealed how participants dealt with the distressing effects of cancer and its treatment. These coping strategies could be classified as adaptive and maladaptive and were endorsed across studies and participant age and diagnoses groups.

Many participants noted the importance of religion or spirituality in providing them with a sense of reassurance during cancer treatment and perceived that their disease outcome was under religious control: “To finish this treatment, I went to church, prayed, and thank[ed] God everything is right!” (Sposito et al., 2015, p. 147). Certain participants, however, believed religion was brought into their lives by people around them only because they were sick (Flavelle, 2011).

With respect to adaptive coping strategies, in the face of the life-threatening nature of cancer and the burden of therapy, children developed a sense of resilience. In particular, they were motivated to get through it (Woodgate, West, & Taylor, 2014), planned coping strategies (Li, Chung, Ho, Chiu, & Lopez, 2011), problem-solved, and were optimistic about their

outcomes. Demonstrating resilience in the face of cancer, one adolescent recounted, “Everybody was like, ‘Oh, you’re gonna die and you’re not gonna be able to walk across the stage [at graduation].’ And I’m like, ‘Watch me!’” (Lam, Cohen, & Roter, 2013, p. 13). One 11-year-old child demonstrated resilience by saying, “I just live the normal life I did before I got diagnosed” (Hildenbrand, Alderfer, Deatrick, & Marsac, 2014, p. 47). School-aged children and adolescents described “getting used to it” (Stewart, 2003, p. 402) with respect to symptoms and functioning within the constraints of treatment: “If people see me, who cares? I’m bald; that’s the way I am” (Barrera et al., 2005, p. 193).

In contrast to resilience, other participants used disease denial to cope with the cancer diagnosis. Participants ranging in developmental stage from toddler to adolescent used denial to cope with cancer early in the treatment process in particular (Ångström-Brännström & Norberg, 2014; Gibson et al., 2013). Rather than engaging with their healthcare team and demonstrating problem-solving during the cancer care process, children who coped using denial longed to return to being normal kids (Woodgate et al., 2014). This was exemplified through their discussions of activities they missed, how friends without cancer were not likewise limited, and their plans to reengage in activities post-treatment. Denial represented a maladaptive coping strategy and was associated with negative consequences for the child. For instance, hesitation to ask for help from the healthcare team resulted in missed opportunities to mobilize: “[I was] too stubborn. Didn’t want to admit I needed help. Look at where that got me” (Flavelle, 2011, p. 29).

New Roles and Responsibilities of the Child

The diagnosis of cancer and associated treatments and procedures demanded that children and adolescents assume roles and responsibilities they had never previously had.

Cancer treatment gave participants a heightened awareness of their mortality, a topic they had not considered in-depth previous to their diagnosis. Even when they had a favorable prognosis, participants described thinking that “death was certain” (Li, Chung, & Chiu, 2010, p. 51). Dying was not the only worrisome thought; children also worried about the effect of their death on their families. In considering their death, participants gauged their potential for survival on the outcomes of other patients, with one stating, “I hoped that I would not die because of the death of a student who I knew” (Ishibashi et al., 2010, p. 80).

In addition, participants articulated the perceived gravity of their disease and the emotional and financial effects it had on their family. They felt a new duty to comfort their loved ones when possible. Children described feeling “stress . . . and responsible for their [parents’] stress” (Woodgate et al., 2014, p. 149). Participants, particularly those with poor prognoses, described engaging in aggressive disease-directed therapy because family members did not want them to quit.

The idea that cancer therapy would not be successful resonated with participants regardless of health gains made during cancer treatment, providing a sense that they were in uncertain territory. Feelings of uncertainty were attenuated by rapid changes in health status. For example, one adolescent stated,

I was kind of like expecting the worst, but when it didn’t get bad the day after, I was just, “I’m gonna be okay then.” And then, tables turned, and they were like, “No, we were just kidding. You’re only okay for a little while.” (Docherty et al., 2006, p. 303)

Uncertainty was an antecedent to children and adolescents’ fear: “I was very worried about the result of

FIGURE 3. Exemplary Quotations Providing Evidence for Fluctuating Realities

Celebrating high points amid low points

- “Well, I’ve got one thing [that is really important to me], and I basically put that in my mind every time I’ve got something hard [to do] and I have to get over it. . . . My cat . . . she’s just a good memory to me, and even though she is a cranky, old thing, I still love her.” (8 years old) (Griffiths et al., 2011, p. 87)

Fighting the treatment, not the cancer

- “I don’t want to . . . it hurts. Dad, I don’t want to [have a port-a-cath needle inserted].” (3 years old) (Björk et al., 2006, p. 216)
- “Well, it’s a feeling that I had for a while. . . . It didn’t seem right. It just didn’t make any sense to me that for my body to get better, I [had] to completely break it down and get sick. . . . It just didn’t seem right . . . that it couldn’t take the pain away.” (16 years old) (Docherty et al., 2006, p. 304)

Preparing for the worst, hoping for the best

- “I was kind of like expecting the worst, but when it didn’t get bad the day after, I was just, ‘I’m gonna be okay then.’” (16 years old) (Docherty et al., 2006, p. 303)

my treatment. I was afraid of unsuccessful treatment” (Nguyen, Nilsson, Hellström, & Bengtson, 2010). This sense of worry arose at diagnosis and pervaded the period of intense therapy, occurring across participant age groups and dates of studies.

Feeling stigmatized because of cancer was discussed primarily by adolescents, who used it as rationale for avoiding social interactions, such as returning to school (Larouche & Chin-Peuckert, 2006). One adolescent shared,

They called me “cancer boy.” . . . A girl who I knew before [I got sick] . . . said to me, “Don’t talk to me.” . . . I thought very seriously about leaving. (Al Omari & Wynaden, 2014, p. 4)

Practical Resources to Enable Managing Cancer

Children and adolescents with varied cancer diagnoses identified several items that mitigated the negative effect of cancer on their lives, which could be provided by nurses and other clinicians.

FIGURE 4. Exemplary Quotations Providing Evidence for Coping Strategies

Denial

- “I just don’t really think about [my cancer]. . . . When somebody tries to help me, I push them off ‘cause I don’t want to think about everything.” (12 years old) (Hildenbrand et al., 2014, p. 47)
- “I want to wear Snow White’s dress. I’m going to put the tie on top of the hat. . . . Now I’m a princess forever. I don’t have cancer.” (9 years old) (Melo Lde & do Valle, 2010, p. 513)

Developing resilience

- “[I] just deal with it and know that by the time this is all over, I’m going to be better and 100% cancer free.” (11 years old) (Hildenbrand et al., 2014, p. 46)
- “It has actually made me a better person. I have always been tense, angry, and selfish. I feel I need my family more. I’m more emotional, I cry more [teary eyed]. I just have a better attitude toward life.” (Momani et al., 2015, p. 53)
- “I just kind of gradually started to realize what I was going to have to go through and stuff.” (Stewart, 2003, p. 402)

Relying on a sense of spirituality

- “People have, like, energies inside of us . . . to, like, cure ourselves.” (Barrera et al., 2005, p. 194)
- “I’m handling [being sick] good so far, thanks to the good Lord.” (Momani et al., 2015, p. 53)

Across primary studies, children and adolescents commonly considered social support to enable them to “feel better about cancer and treatment” (Hildenbrand et al., 2014, p. 47). Participants described family, old friends, other young patients, and healthcare providers as sources of social support.

The good memories of nurses will stay in my mind; they are so kind. . . . They always remind me that I am not alone, and they are my friends. . . . Sometimes, they play with me or tell stories. . . . When I am sad, they make funny faces. (Manookian, Nasrabadi, & Asadi, 2014, p. 317)

Adolescents particularly endorsed the need for support from friends to shield them from perceived negative attention and stigmatization. Many participants advocated for contact with age-matched peers during hospitalization.

In addition, children and adolescents frequently discussed needing disease- and treatment-related information to help them “calm down” (Stegenga & Ward-Smith, 2009, p. 77) and to not assume the worst. Children who were not given information about treatment procedures, the disease, and their prognosis experienced uncertainty and fear. Information was linked to empowerment, with one child stating, “Explain things to me before. Explain them to me early and [explain] well. You know, so I can understand. Understanding is important to me” (Weaver et al., 2015, p. 4421). Participants also noted that their healthcare team should assume responsibility for providing cancer-related information rather than placing the onus on children and adolescents to ask.

They also commonly described the use of practical approaches to cope with symptoms and treatment effects and to mitigate the negative effects of cancer on their lives. Commonly, participants referred to the use of psychological and physical self-management strategies, such as deep breathing (Moody, Meyer, Mancuso, Charlson, & Robbins, 2006), role rehearsal, “distraction[s] like watching TV” (Hildenbrand, Clawson, Alderfer, & Marsac, 2011, p. 349), and the continuation of activities that were part of their lives before cancer. Participants were proud of the strategies they used and were keen to recommend them to other children.

Participants of all ages discussed the importance of having access to developmentally appropriate cancer care services. For younger patients, this meant having access to their parents and being able to play. Adolescent participants advocated for care services that are targeted to their demographic as opposed

to being focused on younger children or adults. Adolescents specifically discussed the need for contact with age-matched peers and to not be treated like younger children by healthcare providers.

Likewise, children and adolescents wanted to “be responsible for [their] own health” (Li et al., 2011, p. 973). They wanted to be included in treatment decision making, practically assist their healthcare team, and be given opportunities to ask questions. Participants expressed frustration and resentment toward care providers and parents who did not recognize their autonomy: “No one would listen to me, as usual. That’s getting really annoying” (Flavelle, 2011, p. 29). When children and adolescents participated in procedures and decision making, they more often facilitated care by cooperating and helping (Björk, Nordström, & Hallström, 2006).

Participants were clear about their distaste for being hospitalized, with one stating, “One hour in the hospital is like 85 hours at home” (Rindstedt, 2014, p. 580). The hospital was a constant reminder of illness and a barrier to engaging in usual activities. Participants made several practical suggestions to improve hospitalization, such as minimizing noise, promoting sleep, providing fun and child-directed activities, supplying better food (Moody et al., 2006), and offering outpatient therapy when possible to minimize the disruption cancer care caused to their lives.

Discussion

The diagnosis of pediatric cancer, the life-threatening nature of the disease, and the intensity of associated therapy have profound short- and long-term effects on children and adolescents’ physical, psychological, social, and developmental health. This study highlights the ways in which cancer changes the lives of children and adolescents undergoing cancer therapy. In particular, young patients described suffering physically with symptoms like pain and nausea, emotionally with feelings of anxiety and sadness, and socially with isolation from friends and changing relationships with their families.

Children coped with the life changes in a variety of ways. Some preferred to deny the disease, whereas others normalized cancer or developed a sense of resilience. Children assumed new roles and responsibilities in the face of cancer, including dealing with their own mortality and living with uncertainty, fear, and stigmatization. These themes, including physical and social burdens, shifting roles and responsibilities, and fear and uncertainty, agree with themes identified

in qualitative syntheses of pediatric survivors, suggesting that children’s perceptions of the effect of cancer on their lives extends beyond the end of active therapy (Manning, Hemingway, & Redsell, 2014; Nightingale et al., 2011; Woodgate, Tailor, Yanofsky, & Vanan, 2016). In addition, to mitigate the negative effect of cancer therapy, children and adolescents made practical suggestions that may be used to inform improvements to the cancer care services.

The authors observed differences in how cancer treatment was framed by participants. In particular, a number of participants described getting used to

FIGURE 5. Exemplary Quotations Providing Evidence for New Roles and Responsibilities of the Child

Coming to terms with the possibility of death

- “At Christmas, I won’t be here anymore. . . . I’m going to be far away. . . . I’m going to die. . . . I’m very scared.” (6 years old) (Melo Lde & do Valle, 2010, p. 516)
- “Dying is as natural as living. It is one’s destiny.” (15 years old) (Yeh, 2002, p. 235)

Facing stigmatization

- “Look at me. I’m not nice looking at all; there will never be a girl that would want to go out with me.” (15 years old) (Larouche & Chin-Peuckert, 2006, p. 204)

Living with uncertainty and fear

- “I’m scared of not seeing my family and staying in the grave alone. I thought about death when I was very tired, when I was admitted to the ICU. I even told my mum, if I died, to bury me near the house because I’m afraid to be alone.” (Al Omari & Wynaden, 2014, p. 5)
- “I felt stress and uncertain by the expressionless faces of the doctors in the ward because I would never know whether the news they brought to me was good or bad.” (Li et al., 2010, p. 51)
- “I was very afraid of pain [crying]. I just wanted to go home. I didn’t want to be injected any more [crying].” (Nguyen et al., 2010, p. 148)

Protecting loved ones

- “I often comfort my mother and father, but mostly my mother when she cries . . . with a hug.” (Ångström-Brännström & Norberg, 2014, p. 142)
- “It has affected my parents’ finances, and I pray God should always provide for them. They are both not earning big, and I also have younger ones, and the little they get goes to my treatment.” (Adejoh et al., 2013, p. 765)

cancer treatment and being resilient to its potential negative effect, but others did not demonstrate these coping skills. The latter participants were physically, psychologically, and socially burdened by cancer; longed to return to their lives before the disease; and were “not up to the challenge” (Docherty et al., 2006, p. 305) of cancer treatment. These findings highlight how cancer treatment affects children along a spectrum of interference, with some children noting the effect to be far more burdensome than others. Known reasons for this variation include medical (e.g., diagnosis, prognosis), treatment (e.g., type of treatment, symptom burden), child (e.g., age, gender), and family (e.g., ethnicity, socioeconomic) variables (Bhatia et al., 2012; Hudson et al., 2014; Klosky et al., 2015; Knafl et al., 2013; Landier et al., 2011; Lightfoot et al., 2012; Metzger et al., 2008; Rosenberg, Macpherson, Kroon, & Johnson, 2013). Additional reasons for various experiences of children with cancer may relate to individual physical and psychosocial responses to treatment. Interventions that promote resilience, optimism, and hope in the face of cancer-related adversity can improve satisfaction with life and decrease anxiety and depression in children and their

families (Eustache, Jibb, & Grossman, 2014; Fotiadou, Barlow, Powell, & Langton, 2008; Rosenberg, Yi-Frazier, Wharton, Gordon, & Jones, 2014). Ultimately, as is done in disease therapy, quality-of-life interventions that are precisely targeted at child-level variables (e.g., medical, physical, psychosocial) may improve the experience of some children. However, because children exist within the complex structure of family units, these resilience-, optimism-, and hope-based interventions must also be flexible, considering family dynamics and family patterns of disease management (Rosenberg et al., 2014). For instance, families that incorporate their child’s needs into their usual routines demonstrate better child and family functioning than those that focus on the child’s special needs at the expense of the family’s needs (Knafl et al., 2013). This suggests that education by healthcare providers that reinforces condition-focused care narratives rather than family-focused care may not be the most optimal means of promoting positive health-related outcomes for children.

After diagnosis, participants in this review also found themselves assuming new roles and

FIGURE 6. Exemplary Quotations Providing Evidence for Practical Resources to Enable Managing Cancer

Autonomy

- “I was 15 when I was diagnosed, so I was already like not really a kid anymore, and so I decided maybe a year later, maybe less than that, that I wanted to get my own pills and organize them myself. That was actually kind of difficult for my mom to sort of give that job over to me.” (Malbasa et al., 2007, p. 147)

Developmentally appropriate services

- “Like I realized that it’s been three months that I was in hospital. I don’t think younger kids really think about the time that they’re spending in here too much. I’m thinking, well, I got to finish high school. I got to do this and this and this, preparing for my independent life . . . it’s harder.” (17 years old) (Woodgate et al., 2014, p. 150)

Disease and treatment information

- “No one said anything about the process; at first, I thought it was like a surgery, and I was very afraid because I didn’t know what was going on, and sometimes I thought it would be a very painful procedure. They should have given me more explanation about the treatment.” (14 years old) (Manookian et al., 2014, p. 317)

Means to alleviate treatment effects

- “The pain isn’t so bad. It hurts a little, but then I already know it hurts, so I do some massage.” (12 years old) (Sposito et al., 2015, p. 146)

Means to deal with hospitalization

- “There is nothing I like here at the hospital. You have to eat when others want you too, sleep too . . . and playing only when you’re not doing chemo.” (6 years old) (Melo Lde & do Valle, 2010, p. 513)
- “It was easier because I didn’t have to miss as much school [when receiving chemotherapy in the ambulatory setting]. That was probably the main reason . . . I’d be feeling frustrated because I was getting behind in school.” (Stevens et al., 2006, p. 280)

Social support

- “I need everyone to visit me. . . . They will relieve my suffering.” (Al Omari & Wynaden, 2014, p. 3)
- “My friends are not like nerds; they are not rejects; when I am with them, we are 10–15 persons together. . . . My friends, [they are] like my metal shield, like a bubble on top of me; if somebody will say something about me, they won’t be scared to defend me.” (15 years old) (Larouche & Chin-Peuckert, 2006, p. 205)

responsibilities that differed from those of their healthy peers. Children were acutely aware of their own mortality and lived with fear and uncertainty. They also felt an emergent need to protect loved ones and set new priorities. These new roles may partially explain why patients and parents report worry and stress as common cancer-related symptoms in children (Hedén, Pöder, von Essen, & Ljungman, 2013). Healthcare provider support, including physical and psychosocial supportive care and education, can alleviate symptoms, promote understanding of the value of treatment, and support patient and family self-management of the new roles children assume while ill (Modi et al., 2012).

Children and adolescents made several suggestions to improve the quality of pediatric cancer care services. Social support was considered a needed resource for participants. Social support has been shown to be effective in improving quality of life, decreasing anxiety and depression, and buffering the negative effects of stress in adult oncology (Luszczynska, Pawlowska, Cieslak, Knoll, & Scholz, 2013; White et al., 2011). However, many children with cancer have limited access to this resource (Bleyer, 2002; French et al., 2013), creating a need for interventions in this vein.

Participants also suggested information to promote understanding of the disease and its treatment and to support engagement in management is needed. This finding aligns with published research showing children's explicit desire for information related to cancer during and after treatment to facilitate coping with the physical and psychosocial disease burden (Stinson et al., 2012; Wright, Coad, Morgan, Stark, & Cable, 2014). Educational interventions focused on children with cancer are currently under development and represent promising avenues to improve patient experiences (Stinson, Gupta, et al., 2015). In addition, children advocated for this information and other cancer care services to be delivered in a developmentally appropriate manner that respected their autonomy. Participants also highlighted the practical strategies they used to mitigate the negative effects of treatment, including pain, distress, and isolation. Tips and tricks acquired over the course of treatment, viewed as accomplishments by children with pediatric cancers, have been discussed in the literature and may represent a growing need to more fully engage in disease self-management (Stinson et al., 2012).

In addition, participants expressed an aversion to being hospitalized, which agrees with research

KNOWLEDGE TRANSLATION

- To complement traditional, medically focused outcomes and to provide a comprehensive picture of treatment effectiveness, healthcare personnel must consider the pediatric patient perspective related to life during cancer care.
 - Children and adolescents with cancer find themselves and their families changed, simultaneously live in juxtaposed realities, are physically and psychosocially burdened by therapy, face stigmatization, and long for normalcy.
 - Children and adolescents describe their capacity to develop resilience and suggest that developmentally appropriate services and information that respect the child's autonomy are needed to practically manage life with cancer.
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showing the immense effect of hospitalization on children with cancer and their families (Ångström-Brännström, Norberg, Strandberg, Söderberg, & Dahlqvist, 2010; Berríos-Rivera, Rivero-Vergne, & Romero, 2008). This may be related to impaired social functioning of the family and the physical (e.g., lack of sleep) and financial burdens of hospitalization (Lyu, Kong, Wong, & You, 2015; Tsimicalis et al., 2013). Other means to support outpatient care, including home-based chemotherapy and the management of treatment-related adverse effects occurring outside the hospital, are needed. Developments in pediatric cancer care services, which increasingly deliver therapy on an outpatient basis, may address children's concerns about hospitalization. However, research is required to determine the acceptability of outpatient and home-based therapy according to children, families, and clinicians.

Limitations

A number of study limitations should be addressed. The authors excluded all studies that were not published in English and, therefore, could not comment on the experiences of children recorded in non-English publications. Most studies were representative of the experience of children treated in high-income countries. The transferability of the themes, however, was improved by including studies from 16 countries, reflecting variable pediatric cancer care practices and patient ethnicities. In addition, the authors analyzed only the results section of the included studies and may have missed some data to include in the analysis. This review analyzed only the views of children and adolescents; the views of parents, siblings, friends, and healthcare providers were excluded. However, the

themes and subthemes that emerged from this study are in close agreement with those of qualitative thematic syntheses of the experiences of childhood cancer survivors and children's families (Manning et al., 2014; Mu et al., 2015; Nightingale et al., 2011; Woodgate et al., 2016). The authors also analyzed data from children with a wide variety of cancer diagnoses from all major childhood cancer types (i.e., hematologic, solid tumor, and central nervous system tumors). This may improve the transferability of the findings, but the authors cannot comment on any differences in experiences during cancer therapy by disease type.

Implications for Nursing

Because this research has comprehensively reviewed the current qualitative literature on the experiences of pediatric patients with cancer, it may inform nursing practice related to childhood cancer treatment. An understanding of the patient perspective is required to provide a comprehensive picture of treatment effectiveness. Considering the profound changes a cancer diagnosis and the associated treatment have on the pediatric patient with cancer, and how these changes vary across individuals and families, will allow nurses to provide the best quality physical and psychosocial care to children and adolescents. Children have articulated that nurses are important sources of social support and improve the cancer care experience. Nurses should provide children and adolescents with disease- and treatment-related information, valuing their developmental stage and autonomy, and prioritize symptom management support to improve quality of life. An understanding of childhood experiences of cancer therapy should direct nursing research-related activities to ensure that activities are targeted to the wants and needs of the research consumers. Interventions should consider family-based resilience philosophies that support families to adapt to the new demands of cancer but also attempt to maintain a semblance of family normalcy (Rosenberg et al., 2014).

Conclusion

Children and adolescents are profoundly affected by cancer treatment. Young patients find themselves and their families changed, live in a juxtaposition between changing realities, are physically and psychosocially burdened by therapy, face stigmatization, and long for normalcy but can also develop resilience. This study evaluated the child's perspective to provide guidance on how cancer treatment affects children and how their experience can be improved. Knowledge acquired through this research may be used to shape

pediatric cancer care practices and services moving forward, ensuring that they are acceptable to and appropriate for young patients.

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The authors gratefully acknowledge Cheri Nickel, MLS, for her invaluable assistance in developing the search strategy used for this review.

During the writing of this article, Jibb was supported by a doctoral research fellowship from the Pediatric Oncology Group of Ontario, and Stinson was supported by a Canadian Institutes of Health Research Peter Lougheed New Investigator Award.

Jibb and Stinson contributed to the conceptualization and design. Jibb, Croal, Wang, and Cheung completed the data collection. Jibb provided statistical support. Jibb, Croal, Yuan, Foster, Cheung, Gladstone, and Stinson provided the analysis. Jibb, Croal, Foster, Gladstone, and Stinson contributed to the manuscript preparation.

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