


Experiences of Pediatric Oncology Patients and Their Parents at End of Life: A Systematic Review

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Abstract

Improvement in pediatric palliative and end-of-life care has been identified as an ongoing research priority. The child and parent experience provides valuable information to guide how health care professionals can improve the transition to end of life and the care provided to children and families during the vulnerable period. The purpose of this systematic review was to describe the experience of pediatric oncology patients and their parents during end of life, and identify gaps to be addressed with interventions. A literature search was completed using multiple databases, including CINAHL, PubMed, and PsycInfo. A total of 43 articles were included in the review. The analysis of the evidence revealed 5 themes: symptom prevalence and symptom management, parent and child perspectives of care, patterns of care, decision making, and parent and child outcomes of care. Guidelines for quality end-of-life care are needed. More research is needed to address methodological gaps that include the pediatric patient and their sibling's experience.

Keywords

cancer, pediatric oncology, end of life, child, parent

Seventeen out of 100 000 children aged 0 to 19 years are diagnosed with cancer annually in the United States (Howlader et al., 2011). Worldwide, an estimated 175 300 new cancer cases occurred in children aged 0 to 14 years (American Cancer Society, 2011). Advancements in cancer, including targeted therapies, have been reported to contribute to an 80% long-term survival of all children with cancer (Bernstein, 2011; Howlader et al., 2011). Despite advances in pediatric oncology treatments and technology, some children with cancer may die while receiving oncology treatments or from their disease (Kurashima, Latorre Mdo, Teixeira, & De Camargo, 2005).

The symptomatology trajectory for children and adolescents undergoing cancer treatment often varies. It has been reported that many children who die a cancer-related death may die while experiencing 2 to 8 poorly controlled symptoms, such as pain, poor appetite, dyspnea, fatigue, nausea/vomiting, constipation, and anxiety (Hinds, Pritchard, & Harper, 2004; Hongo et al., 2003). Prevention of suffering, including effective symptom management, in children dying of cancer is a central value for clinicians in pediatric oncology (Hinds, Drew, et al., 2005).

Pediatric oncology nurses play a central role in the development and provision of the child's plan of care.

The discipline of nursing transcends multiple settings, providing continuity across wellness and illness trajectories. End of life (EOL) is a vulnerable time for children, adolescents, and their families. Pediatric oncology nurses, along with interprofessional partners, may influence EOL outcomes, such as the assessment of symptoms and associated distress, symptom management, decision-making processes with the child and family, and quality transitions across settings (McDonald & McCallin, 2010; Nuss, Hinds, & LaFond, 2005).

Palliative care (PC) and EOL are concepts that have continued to gain relevancy in the community, health care, and research settings. The World Health Organization (2012) defines PC in children as "active total care of the child's

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body, mind and spirit,” providing “support to the family . . . [beginning] when illness is diagnosed, and [continuing] regardless of whether or not a child receives treatment directed at the disease.” Despite agreement from an international organization on the definition of PC, structures and services to support such a comprehensive definition have been slow to develop. Progress has been made in some countries, including the United States where PC has evolved to address the needs of a wide range of patients who may not be termed *dying*, but for whom alleviation of suffering and improvement in quality of life may be relevant goals (Meghani, 2004). Similarly, organizations in other countries including the United Kingdom support defining palliative care as a comprehensive approach to care that starts at diagnosis and continues throughout the child’s life, death, and beyond (Together for Short Lives, 2014).

In contrast to PC, EOL lacks a consistent definition in the literature. Within the United States, the National Institutes of Health (2004) identified the following components of EOL: (a) presence of chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate and (b) symptoms or impairments resulting from the underlying irreversible disease which require formal or informal care and can lead to death. Generally, EOL is considered supportive care provided to individuals and families at the terminal phase of life. As part of the growing emphasis to enhance understanding of EOL, National Institute of Nursing Research (NINR, 2011) identified EOL for pediatric patients with cancer as a research priority with a focus on the impact of health care professionals’ communication with the child and family, and health outcomes associated with health care professionals trained in providing care at EOL. Furthermore, research has led to the 2014 NINR campaign *Palliative Care: Conversations Matters®*, which aims to help patients, families, and health care providers (HCPs) discuss PC earlier (NINR, 2014).

Research Question

What are the PC/EOL care experiences of children with cancer and their parents? The scope of the review included parents of children with cancer and excluded other family members, including siblings and grandparents because other family members may have different experiences than parents and may benefit from a specific and separate inquiry.

Methods

Search Procedures

In order to conduct a review, a literature search was completed. Multiple databases were searched including CINAHL, PubMed, and PsycInfo. An additional manual

reference search was conducted from the initial articles retrieved. Key words included “symptom management,” “end of life,” “end of life care,” “palliative care,” “terminal care,” “death,” “dying,” “hospice*,” “child*,” “pediatric*,” “parent*,” “neoplasm,” “cancer,” and “tumor*.”

Inclusion and Exclusion Criteria

Exclusion criteria were used to refine the initial search and excluded publications prior to 2000 and those not published in the English language, with the exception of seminal work, and publications that were not peer-reviewed. Following a manual review of references, additional articles meeting search criteria were included in the sample. Studies in the English language addressing child/parent experience at EOL were chosen for further analyses. Research studies focused on child and parent experiences during PC and EOL were included, but general studies of PC were not included.

Review Parameters

The selected articles were reviewed and analyzed for common themes, and those themes were used to organize and discuss the findings in this review article. The evidence-leveling system by Melnyk and Fineout-Overholt (2005) was used to rate the evidence for this literature review. The system includes 7 levels of evidence, which were used to provide a consistent and comprehensive list of evidence (Melnyk & Fineout-Overholt, 2005). An analysis of the evidence was conducted to identify themes across studies. Individual studies were labeled with the following elements: content area(s) based on their research question(s), study population, study setting, and methodology.

Results

A final pool of 43 articles was retained for inclusion in this review article. For a summary of the literature and article selection refer to Figure 1. The majority of the selected studies were rated at Level 6 (evidence from a single descriptive or qualitative study). Two studies were rated at Level 4 (evidence from well-designed case-control and cohort studies). The majority of studies reviewed used descriptive designs.

Analysis of the evidence revealed 5 themes: (a) symptom prevalence and symptom management, (b) parent and child perspectives of care, (c) patterns of care, (d) decision making, and (e) parent and child outcomes of care. Results of the analysis are reported by theme followed by a critique of the quality of the literature. Refer to Table 1 for a complete summary of the evidence listed by theme and publication year of each reviewed article.

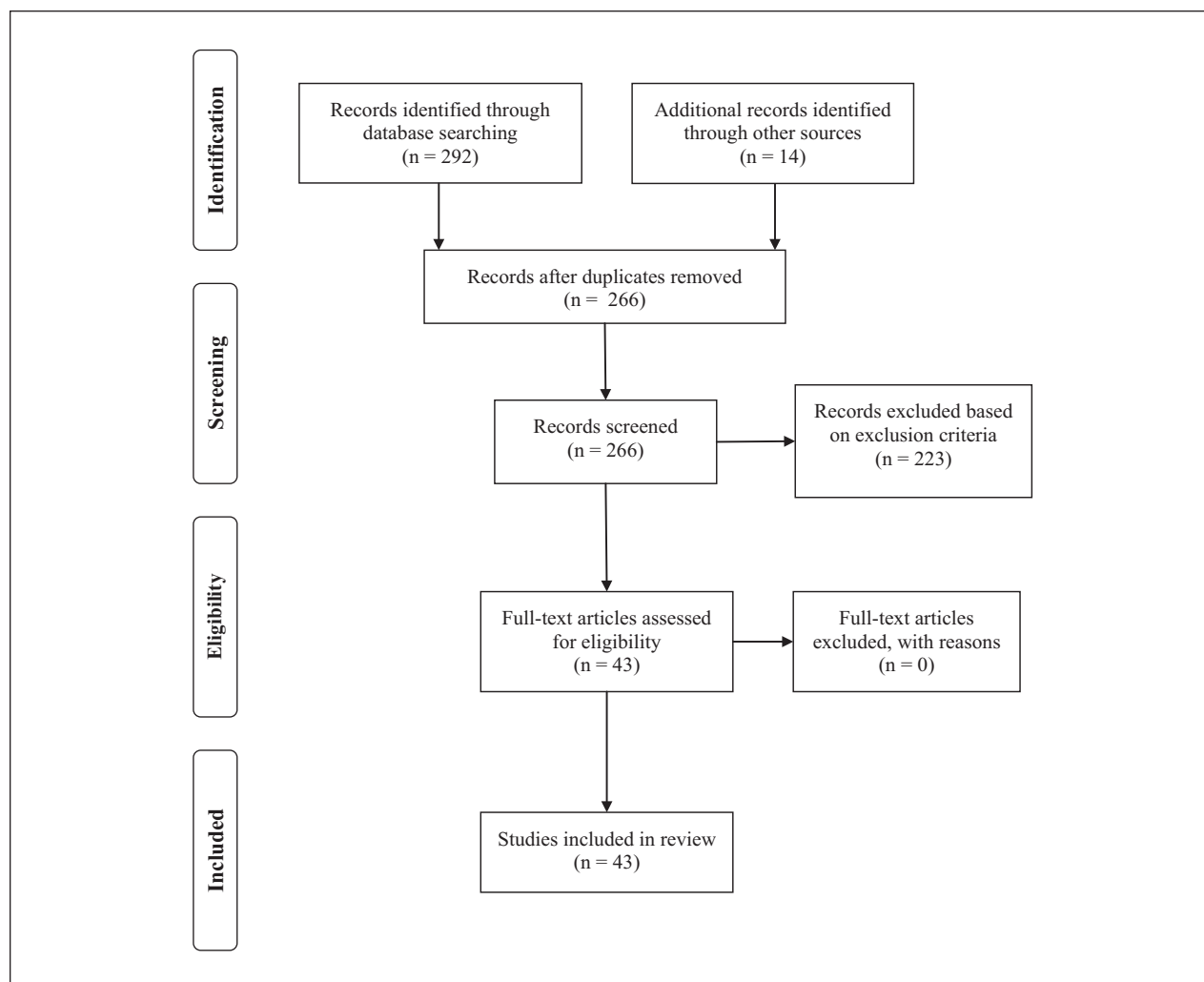


Figure 1. Summary of literature search and article selection.

Results of Thematic Analysis

Symptom Prevalence and Symptom Management. Ten of the studies focused on symptoms experienced by children with cancer during EOL. The most frequently cited symptoms included pain, changes in breathing or dyspnea, changes in motor function, difficulty swallowing, fatigue, changes in appearance, nausea/vomiting, and anxiety (Collins et al., 2000; Heath et al., 2010; Hendricks-Ferguson, 2008; Hongo et al., 2003; Jalmsell, Kreicbergs, Onelöv, Steineck, & Henter, 2006; Pritchard et al., 2008; Pritchard et al., 2010; Theunissen et al., 2007; Wolfe et al., 2000; Zhukovsky, Herzog, Kaur, Palmer, & Bruera, 2009).

Seven studies evaluated pain management strategies used during EOL through retrospective medical record review or case studies. All but one study (Hendricks-Ferguson, 2008) described the management of pain as a

single symptom, and most reflected the use of pharmacologic agents independently of other adjuvant therapies (Angelescu, Faughnan, Baker, Yang, & Kane, 2010; Hooke, Hellsten, Stutzer, & Forte, 2002; Orsey, Belasco, Ellenberg, Schmitz, & Feudtner, 2009). Opioid therapy was the most studied pain intervention at EOL. Studies have shown that more than 50% of children who die a cancer-related death received some degree of opioid therapy during EOL (Bell, Skiles, Pradhan, & Champion, 2010; Orsey et al., 2009).

Additional studies evaluated the use of continuous and intermittent opioid interventions for pain in pediatric oncology patients (Angelescu et al., 2010; Houlahan, Branowicki, Mack, Dinning, & McCabe, 2006; Schiessl, Gravou, Zernikow, Sittl, & Griessinger, 2008). Angelescu, Hamilton, Faughnan, Johnson, and Baker (2012), Hooke et al. (2002), and Conway, White, St. Jean, Zempsky, and Steven (2009) used continuous propofol

Table 1. Summary of Evidence for Patient and Parent Experiences During End of Life.

Author(s) (Year); Country; Methods	Sample	Conclusions
<i>Symptom prevalence and symptom management</i>		
Anghelescu, Hamilton, Faughnan, Johnson, and Baker (2012); United States; QT	3 pediatric oncology patients	<ul style="list-style-type: none"> • Propofol sedation was found to alleviate anxiety and agitation even when pain could not be adequately controlled • Opioids dose was reduced in 1 patient and had no or minimal change in 2 patients • Patients received propofol between 2 and 8 days
Anghelescu, Faughnan, Baker, Yang, and Kane (2010); United States; QT	10 pediatric oncology patients	<ul style="list-style-type: none"> • Length of epidural use (4-57 days) and peripheral nerve block use (3-81 days) • 12 of 13 (93%) pain blocks improved pain control reflected in change in mean pain score
Heath et al. (2010); Australia; QT	100 parents of 96 pediatric oncology patients	<ul style="list-style-type: none"> • Patients who received cancer-directed therapy during EOL significantly suffered from more symptoms than those who did not receive therapy • Severity of symptoms did not differ from those who received cancer-directed therapy than those who did not • Symptoms most frequently reported: pain, fatigue, and poor appetite • 84% of parents reported their child a lot or great deal of suffering from at least 1 symptom (43% from 3 or more) • Most commonly treated symptoms: pain (95%), constipation (74%), nausea/vomiting (70%)
Pritchard et al. (2010); United States; MX	52 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Symptoms of most concern: change in behavior (23.62%) change in breathing (16.01%), pain (16.01%), difficulty swallowing (2.34%), weakness/fatigue (5.47%), and vomiting (4.5%) • Factors influencing level of most concern: unrelieved parental or child distress (39.85%), new or unexpected symptom (39.45%), and behavioral and emotional change (10.35%) • Factors influencing no concerns: symptoms present for at least 1 week (33.94%), symptoms that cause no distress (12.84%), symptoms that were well managed (8.26%)
Zhukovsky, Herzog, Kaur, Palmer, and Bruera (2009); United States; QT	15 pediatric oncology patients	<ul style="list-style-type: none"> • Median number of documented symptoms at point of consultation was 5 per child (range = 2-10) • PC consultation universally resulted in detection of symptoms not identified by the primary HCP team (median = 3 new symptoms per patient) • Documented communication about EOL care issues with parents was uncommon and rarely involved children • PC consultation resulted in recommendations for medication changes in 14 out of 15 children, allied health consultation in 8, counseling in 11, patient care conference in 3, family conference in 6

(continued)

Table 1. (continued)

Author(s) (Year); Country; Methods	Sample	Conclusions
Orsey, Belasco, Ellenberg, Schmitz, and Feudtner (2009); United States; QT	1466 pediatric oncology patients	<ul style="list-style-type: none"> • 56% of sample were prescribed opioids daily and 44% received less than daily opioids in last week of life • Patient-level characteristics that increased likelihood of receiving daily opioids: age, broad category of cancer diagnosis, and length of hospital stay • Hospital-level characteristics accounted for variation in daily opioid prescription during last week of life
Conway, White, St. Jean, Zempsky, and Steven (2009); United States; QT	2 pediatric oncology patients	<ul style="list-style-type: none"> • Decrease in rate of opioid dosage increased with pain plan • Decrease in opioid related side effects with pain plan
Hendricks-Ferguson (2008); United States; QL	28 patients of pediatric oncology patients	<ul style="list-style-type: none"> • Symptoms of greatest concern on day of death: changes in breathing (57%), loss of motor function (32%), changes in energy level (29%) • Symptoms of greatest concern during last week of life: loss of motor function (36%), changes in energy level (36%), changes in breathing (32%) • Symptom relief strategies: physical comfort activities (54%), medications (50%), preventive actions for physical symptoms (39%), physical closeness (39%), physical presence (39%)
Pritchard et al. (2008); United States; MX	65 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Most frequently reported symptoms at EOL included: changes in behavior (53.8%), changes in appearance (28.8%), pain (67%), weakness/fatigue (21.2%), and breathing changes (28.8%) • Most helpful interventions by HCPs: pain and anxiety medications (31.3%), being present with the child/family (10.0%), providing competent care (12.5%), and giving anticipatory guidance (6.3%)
Schiessl, Gravou, Zernikow, Sittl, and Griessinger (2008); Germany; QT	8 pediatric oncology patients	<ul style="list-style-type: none"> • Daily opioid IV dose increased by 30% during the last week of life • Pain scores did not change significantly during PCA therapy despite escalating doses of opioids
Hooke, Hellsten, Stutzer, and Forte (2002); United States; QT	9 pediatric oncology patients	<ul style="list-style-type: none"> • Propofol administered intravenously improved QOL at EOL
Theunissen et al. (2007); Netherlands; QT	59 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Mean number of symptoms during EOL was 6.3 (SD = 2.7) • Most frequently reported physical symptoms: pain (75%), poor appetite (75%), fatigue (72%), lack of mobility (66%), vomiting (53%) • Most frequently reported psychological symptoms: sadness (65%), difficulty talking about feelings (41%), fear of being alone (37%), loss of perspective (36%) • No statistical difference in number of symptoms between tumor types

(continued)

Table I. (continued)

Author(s) (Year); Country; Methods	Sample	Conclusions
Jalmsell, Kreicbergs, Onelöv, Steineck, and Henter (2006); Sweden; QT	449 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Most frequently reported symptoms with high or moderate impact on child: fatigue (86%), reduced mobility (76%), pain (73%), poor appetite (71%) • No statistical difference in most reported symptoms between tumor types
Hongo et al. (2003); Hong Kong and Greece; QT	28 pediatric oncology patients	<ul style="list-style-type: none"> • Signs and symptoms most experienced at EOL: poor appetite (100%), dyspnea (82.1%), pain (75%), fatigue (71.4%), nausea/vomiting (57.1%), anxiety (53.6%)
Collins et al. (2000); United States; QT	160 pediatric oncology patients	<ul style="list-style-type: none"> • Pain was the most prevalent symptom for inpatient group (84.5%) and was rated moderate to severe by 86.8% and highly distressing by 52.8% of patients • Inpatients experienced significantly greater number of symptoms compared with outpatients (mean = 12.7; 6.5) • Patients who had recently received chemotherapy significantly experienced more symptoms (mean = 11.6).
Wolfe et al. (2000); United States; QT	103 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Most frequently reported symptoms: fatigue, pain, dyspnea, poor appetite • 89% of parents reported their child experienced a lot or great deal of suffering from at least 1 symptom (51% with 3 or more) • Most frequently treated symptoms: pain (76%), dyspnea (65%)—successful treatment in <30% of children • Lack of involvement of an oncologist was associated with significantly more suffering from pain (OR = 2.6; CI = 1.0-6.7).
<i>Parent and child perspectives of care</i>		
Kars Grypdonck, de Korte-Verhoef, et al. (2011); Netherlands; QL	44 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Feelings of loss play a prominent role during EOL • Dealing with loss is reflected as an internal struggle between preservation and letting go • Preservation is characterized as parents trying to maintain the child's status quo • Letting go means parents give up their resistance to loss in order for their child's well-being • Timely completion of parent transition positively influences the child's well-being
Kars, Grypdonck, and van Delden (2011); Netherlands; QL	42 parents of pediatric oncology patients	<ul style="list-style-type: none"> • 4 EOL stages were identified: <ul style="list-style-type: none"> ◦ Becoming aware of the inevitable death ◦ Making the child's life enjoyable ◦ Managing the change for the worse ◦ Being with the dying child • Nurses may play a role in helping parents during EOL

(continued)

Table 1. (continued)

Author(s) (Year); Country; Methods	Sample	Conclusions
Zelcer, Cataudella, Cairney, and Bannister (2010); Canada; QL	25 parents of pediatric oncology patients	<ul style="list-style-type: none"> • 3 themes described the EOL experience: <ul style="list-style-type: none"> ◦ Dying trajectory ◦ Parental struggles ◦ Dying at home • Neurologic symptoms are most experienced during EOL • Loss of communication was a significant turning point in the dying trajectory • Maintaining normalcy and spiritual strength were reported coping mechanisms
Heath et al. (2009); United States; MX	96 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Parents were most satisfied when they received care from the primary care team (oncologists, RNs, etc) • Majority of parents recalled discussions about transition to PC and home • 21% recalled formal discussions about life-sustaining treatments • 70% felt they rarely received conflicting information from HCPs • High ratings of care were significantly associated with parental perceptions that HCPs gave bad news in a sensitive manner, gave clear information about what to expect at EOL, provided feeling of pre-preparedness for medical problems at EOL, communicated directly with the child • Low ratings were significantly associated with parental perceptions of receiving conflicting information
Hendricks-Ferguson (2007); United States; QL	28 parents of pediatric oncology patients	<ul style="list-style-type: none"> • EOL options presented to parents ranged from 2 days to 9 months before death, majority received EOL information <2 months before death • 96% of parents reported EOL options being shared spontaneously late in the dying trajectory • Parents' memories of HCP communication regarding EOL: <ul style="list-style-type: none"> ◦ Positive memories (17%) ◦ Negative memories (50%) ◦ Discussion of EOL during therapy (17%) ◦ No memory of EOL discussions (14%) • Parents' preferences for timing of EOL support: <ul style="list-style-type: none"> ◦ Early introduction (43%) ◦ When treatments have failed (39%) ◦ No recommendation (18%)
Mack et al. (2005); United States; QT	142 parents of pediatric oncology patients and 144 pediatric oncology patients	<ul style="list-style-type: none"> • Physicians' ratings of care were significantly inversely correlated with parent's report of child's experience of pain ($OR = 0.15$) and >10 hospital days at end of life ($OR = 0.24$)

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Table I. (continued)

Author(s) (Year); Country; Methods	Sample	Conclusions
Contro, Larson, Scofield, Sourkes, and Cohen (2002); United States; QL	68 family members of pediatric patients	<ul style="list-style-type: none"> Higher parent ratings of physician care were significantly associated with receiving anticipatory guidance for end of life (OR = 19.90), communicating with care/sensitivity (OR = 7.67), communicating with child (OR = 11.18), and preparing parent for child's death (OR = 4.84). Unsatisfactory interactions with HCPs were identified as confusing, inadequate, or uncaring communications regarding treatment or prognosis
<i>Patterns of care</i>		
Arland, Hendricks-Ferguson, Pearson, Foreman, and Madden (2013); United States; QT	133 pediatric oncology patients; Cohort 1: 22 patients (No EOL care program); Cohort 2: 93 patients (EOL care program)	<ul style="list-style-type: none"> Cohort 1 experienced higher number of admissions, poor symptom control Cohort 2 experienced fewer complications No impact of the EOL care program on death occurring in a hospital setting
Yanai et al. (2012); Japan; QT	18 pediatric oncology patients	<ul style="list-style-type: none"> All patients who died in the ICU (n = 6) received aggressive treatments Preferred location of death: home (n = 4), hospital (n = 2), no preference (n = 1), not assessed (n = 11) Place of death was significantly associated with preference of family (home vs hospital vs none) Patients with hematological disease all died in a hospital setting, with a majority dying in the ICU
Tzuh Tang et al. (2011); Taiwan; QT	1208 pediatric oncology patients	<ul style="list-style-type: none"> 78.8% died in acute care hospital setting 52.5% received chemotherapy in last month of life; 14.3% visited the ER more than once; 32.5% were admitted to the hospital more than once; 60.2% had a length of stay greater than 14 days; 57.0% received care in the ICU in the last month of life; 48.2% were mechanically ventilated; 24.0% received cardiopulmonary resuscitation in the last month of life; only 7.2% of patients received hospice care
Shah et al. (2011); England; QT	1864 pediatric oncology patients	<ul style="list-style-type: none"> 47% died in the hospital, 45% died at home No associations between location of death and gender or participation in clinical trials Children with leukemia or lymphoma were more likely to die in the hospital compared with solid tumors 70% of Asian and Black children died in the hospital; 42% of Caucasian children in the hospital
Bell, Skiles, Pradhan, and Champion (2010); United States; QT	107 pediatric oncology patients	<ul style="list-style-type: none"> 58 adolescents died in a hospital; 16 died at home (missing data for 29)

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Table 1. (continued)

Author(s) (Year); Country; Methods	Sample	Conclusions
Ullrich et al. (2010); United States; QT	141 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Half of hospital deaths occurred in the ICU and of those, most deaths were significantly attributed to treatment-related complications • Aggressive life-sustaining measures occurred in 12% of adolescents • 68% had initial EOL discussions with their oncologist; 50% occurred in the last 30 days of life. • The HSC transplantation group significantly spent more days in the hospital in the last month of life, were more likely to be intubated in the last 24 hours of life, to die in the ICU, and less likely to have a planned location of death or have hospice involved compared with the non-HPCT group • The symptoms most experienced at EOL for both groups included: pain, anorexia, fatigue, nausea/vomiting, dyspnea, and fever or infection
Dussel et al. (2010); United States; QT	140 parents of pediatric oncology patients	<ul style="list-style-type: none"> • 62% of parents were able to plan their child's location of death • Planning was significantly less likely among children with hematological cancers compared with other diagnoses. • Dying from disease progression versus treatment toxicity was significantly associated with likelihood of planning location of death • Parents who had experienced a previous loss were significantly more likely to plan location of death • Parents who reported they strongly agreed that physicians communicated about EOL options were significantly more likely to plan location of death • 97% of parents who planned their child's location of death reported the child died in that location • Parents who planned location of death felt significantly more prepared for medical circumstances around the time of death and being very comfortable compared with parents who did not
Wolfe et al. (2008); United States; QT	119 pediatric oncology patients; Baseline cohort: 102 pediatric oncology patients	<ul style="list-style-type: none"> • Hospice discussions significantly occurred more often (76% vs 54%) and earlier (52 days vs 28 days before death) compared with baseline cohort • DNR orders were documented earlier (18 days vs 12 days) • Deaths in ICUs decreased significantly • Parents significantly reported less suffering from pain and dyspnea • Parents felt significantly more prepared during the child's last month of life
Bradshaw, Hinds, Lensing, Gattuso, and Razzouk, (2005); United States; QT	145 pediatric oncology patients	<ul style="list-style-type: none"> • 45.5% of deaths occurred in the hospital; 30.3% occurred in the home

(continued)

Table I. (continued)

Author(s) (Year); Country; Methods	Sample	Conclusions
Kurashima, Latorre Mdo, Teixeira, and De Camargo (2005); Brazil; QT	71 pediatric oncology patients	<ul style="list-style-type: none"> • Patients who deaths were attributed to cardiopulmonary or cardiovascular events (73.5%) or infection (77.8%) were twice as likely to die in the hospital as those with progressive disease (36.8%) • BMT patients and leukemia patients were more likely to die from complications • Patients with brain tumors were more likely to die at home • DNR order was present in 48.3% of cases and completed a median of 11 days before death (range = 0-409 days) • 73.9% of BMT patients had a documented DNR in their records. • 59% of patients died at home • Male gender and public insurance were significantly associated with dying at home (gender: OR = 3.8; public insurance: OR = 4.9) • No associations between location of death and race, family composition, educational background of patient or father, or religion • Mothers of children with a home care provider who had higher levels of education were likely to have a child who died at home • 10% of sample died with full ICU support
Klopfenstein, Hutchison, Clark, Young, and Ruymann (2001); United States; QT	95 pediatric oncology patients	<ul style="list-style-type: none"> • 35% of total sample received hospice support • The following factors had significant correlation with disease-related death: referral to hospice, diagnosis, inpatient setting, and support being withdrawn
<i>Decision making</i>		
Tomlinson et al. (2011); Canada; QT	26 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Variable correlation among parents in the importance of factors in contributing to cancer-directed therapy versus supportive care. Greatest agreement between couple was observed for: physical health (ICC = 0.4, $P = .022$), pain (ICC = 0.46, $P = .068$), nausea (ICC = 0.61, $P = .017$), fatigue (ICC = 0.50, $P = .047$) • Other family members' QOL was the strongest correlating factor to influence parents' decision for chemotherapy or supportive care alone ($r = 0.68$, $P = .11$)
Maurer et al. (2010); United States; QL	62 parents of pediatric oncology patients	<ul style="list-style-type: none"> • 31 parents chose Phase I therapy; 27 chose DNR or terminal care • Phase I parents: felt compelled to continue cancer-directed therapy • DNR/terminal care parents: desired increased QOL and patient wishes • Common decision factors: medical facts, doing right, opinion of others

(continued)

Table 1. (continued)

Author(s) (Year); Country; Methods	Sample	Conclusions
Hinds et al. (2009) United States; QL	62 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Common themes of good parent: doing right, providing support and presence, and sacrifice for the child • Aspects of the definition of being a good parent included: making informed, unselfish decisions in the child's best interest, remaining at the child's side, showing the child they are cherished, teaching the child to make good decisions, advocating for the child with HCP staff, and promoting the child's health • Clinician strategies represent 3 categories: strategies that parents benefit from and want continued, strategies parents want increased, and strategies parents want initiated • 4 clinician behaviors that support being a good parent: HCPs telling parents they are "good parents," not forgetting the child and family once the child has died, providing more material items and support options, and coordinated care at EOL
Edwards et al. (2008); United States; QT	38 parents of pediatric oncology patients	<ul style="list-style-type: none"> • Majority of mothers and fathers reported less suffering as the primary goal for their child at EOL • When parents disagreed on the primary goal of lessening suffering, both parents were more likely to report that the child suffered significantly from cancer-directed treatment
Pousset et al. (2009); Belgium; MX	38 pediatric oncology patients	<ul style="list-style-type: none"> • In terminal situations it was more acceptable for adolescents to request nontreatment decisions (90%), alleviation of symptoms (84%), and euthanasia (64%) compared with adolescents without a cancer diagnosis • In nonterminal situations, all 3 types of decisions were significantly less acceptable
Hinds, Drew, et al. (2005); United States; QL	20 pediatric oncology patients 19 Parents of pediatric oncology patients	<ul style="list-style-type: none"> • 90% of children accurately recalled all of their treatment options and identified their own death as a consequence of their decision • Factors most frequently identified included: (patients) caring about others (95%), avoiding adverse events (70%), wanting no more therapy (65%), (parents) child's preferences (94.7%), trusting staff and being supported by them (84.2%), deciding as a good parent would do (84.2%)
<i>Parent and child outcomes of care</i>		
McCarthy et al. (2010); United States; QT	58 parents of pediatric oncology patients	<ul style="list-style-type: none"> • 41% of parents met diagnostic criteria for grief-related separation distress • 22% had clinically significant depressive symptoms • Time since death and parental perception of oncologist's care significantly predicted parental grief symptoms ($r = -0.35$) but not depressive symptoms ($r = -0.19$)

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Table 1. (continued)

Author(s) (Year); Country; Methods	Sample	Conclusions
Kreicbergs et al. (2005); Sweden; QT	449 parents pediatric oncology patients	<ul style="list-style-type: none"> • Perceptions of the child's QOL during the last month ($r = 0.43$; $r = 0.37$), preparedness for the death ($r = 0.33$; $r = 0.34$), and perception of oncologist care ($r = 0.62$; $r = 0.29$) significantly predicted grief and depression outcomes, respectively • Total variance for depression was 20.6% ($F = 3.96$); with perceptions of child's QOL and preparedness making significant and unique contributions • 2 most frequent stressors experienced by parents: pain not relieved (45%) and negligent care of child (46%) • 57% of parents who had a child with pain not relieved were still affected by it 4 to 9 years after the child's death • Lack of staff not present at time of death results in an increased probability of parents reporting that their child had a difficult moment of death (relative risk = 1.4, 95% CI = 1.0-1.8)

Abbreviations: QT, quantitative design; QL qualitative design; MX, mixed methods design; CI, confidence interval; SD, standard deviation; OR, odds ratio; ICC, intraclass correlation coefficient; EOL, end of life; QOL, quality of life; HCP, health care provider; ICU, intensive care unit; DNR, do not resuscitate; HSC, hematopoietic stem cell; HPCT, hematopoietic progenitor cell transplantation.

and ketamine as analgesics to manage pain at EOL. Studies focused on evaluating the use of continuous and intermittent opioid and analgesic interventions may provide insight into the direction of future pharmacologic pain management strategies. Hendricks-Ferguson (2008) and Hongo et al. (2003) evaluated the use of multimodal approaches to pain management during EOL, including pharmacologic therapies (opioids, other analgesics, chemotherapy, and radiation therapy) as well as nonpharmacologic therapies (physical presence, comfort activities, and physical closeness).

Only 3 of the studies reviewed specifically discussed outcomes of pain management (Angheliescu et al., 2010; Hooke et al., 2002; Schiessl et al., 2008). Hooke et al. (2002) identified strategies for determining outcomes, including partnering with the patient and family. Additionally, there was variation across the studies in evaluating intervention effectiveness. Schiessl et al. (2008) defined daily dose changes, daily patient-controlled analgesia boluses, and pain scores as outcomes for pharmacologic interventions. Angheliescu et al. (2010) and Hooke et al. (2002) identified patient pain scores as key outcome indicators for evaluating pain interventions.

Parent and Child Perspectives of Care. Parental perspective of EOL care was a key theme supported by 7 studies (Contro, Larson, Scofield, Sourkes, & Cohen, 2002;

Heath et al., 2009; Hendricks-Ferguson, 2007; Kars, Gryphonck, de Korte-Verhoef, et al., 2011; Kars, Gryphonck, & van Delden, 2011; Mack et al., 2005; Zelcer, Cataudella, Cairney, & Bannister, 2010). Five studies used a qualitative design with phenomenological, grounded theory, or content analysis methods (Contro et al., 2002; Hendricks-Ferguson, 2007; Kars, Gryphonck, de Korte-Verhoef, et al., 2011; Kars, Gryphonck, & van Delden, 2011; Zelcer et al., 2010), while one used a quantitative descriptive design (Mack et al., 2005), and one used a mixed methods approach (Heath et al., 2009). Two studies evaluated factors that supported parental ratings of quality EOL care (Heath et al., 2009; Mack et al., 2005). High ratings of care were found to be associated with receiving anticipatory guidance regarding the EOL trajectory, feeling prepared, HCPs communicating with child and parents in a sensitive manner, and communicating directly with the child during EOL (Heath et al., 2009; Mack et al., 2005). In addition, time since death and parental perception of the oncologist's care was shown to moderately predict parental grief symptoms (McCarthy et al., 2010). Furthermore, the child's quality of life during the last month, preparedness for the death, and economic hardship moderately predicted grief and depression outcomes.

Three qualitative studies exploring parental perspectives during EOL provide the beginning groundwork for

developing conceptual frameworks inclusive of the child and parent (Kars, Grypdonck, de Korte-Verhoef, et al., 2011; Kars, Grypdonck, & van Delden, 2011; Zelcer et al., 2010). A timely completion of the parental transition from preservation and treatment to letting go and supporting EOL may be important to the child's well-being during EOL (Kars, Grypdonck, de Korte-Verhoef, et al., 2011). Furthermore, parents identified loss of communication with their child as a significant point in the child's dying trajectory (Zelcer et al., 2010). Each of these studies adds to the understanding of the parent's experience, specifically their needs and stages or transitions from treatment to EOL.

Patterns of Care. Eleven studies evaluated patterns of care at EOL (Arland, Hendricks-Ferguson, Pearson, Foreman, & Madden, 2013; Bell et al., 2010; Bradshaw, Hinds, Lensing, Gattuso, & Razzouk, 2005; Dussel et al., 2010; Klopfenstein, Hutchison, Clark, Young, & Ruymann, 2001; Kurashima et al., 2005; Shah et al., 2011; Tzuh Tang et al., 2011; Ullrich et al., 2010; Wolfe et al., 2008). Patterns of care were similar across countries represented in the sample. The majority of children who die a cancer-related death do so in a hospital setting (acute care or intensive care unit), with smaller numbers of children dying in a home setting (Bell et al., 2010; Bradshaw et al., 2005; Klopfenstein et al., 2001; Kurashima et al., 2005; Shah et al., 2011; Tzuh Tang et al., 2011; Ullrich et al., 2010; Yanai et al., 2012). Location of death for children with cancer was shown to be associated with the following factors: age, diagnosis (hematologic vs solid tumor), cause of death, length of last hospital admission, discussion with HCP regarding EOL, and presence of a do-not-resuscitate order (Bell et al., 2010; Bradshaw et al., 2005; Dussel et al., 2010; Klopfenstein et al., 2001; Shah et al., 2011; Wolfe et al., 2008; Yanai et al., 2012). Children with hematologic malignancy and those with treatment-related complications were more likely to die in the hospital (Shah et al., 2011). The child's diagnosis and type of malignancy influenced the type of symptoms experienced at EOL, which may have contributed to the location of death. Children who died in an acute care or intensive care unit hospital setting often died of treatment-related complications rather than disease progression, or died while undergoing hematopoietic stem cell transplantation. Pediatric oncology patients undergoing hematopoietic stem cell transplantation were significantly more likely to die from treatment-related complications and often had less time to prepare for EOL (Bradshaw et al., 2005; Ullrich et al., 2010). Conversely, children with cancer who have not had hematopoietic stem cell transplantation were more likely to die of disease progression and thus have more opportunity to prepare for EOL (Bradshaw et al., 2005; Ullrich et al., 2010).

Patterns of care during EOL may have been influenced by HCP communication in EOL discussions with the child and family. Although a majority of patients and their parents had an initial EOL discussion with their oncologist, half of these discussions occurred in the last 30 days of the child's life. Many parents believed that the discussions should have been initiated earlier in life (Bell et al., 2010, Hendricks-Ferguson, 2007). When initial discussions about PC or EOL began in the last 7 to 30 days of life, there was minimal time for EOL preparation. Investigators suggested that delays in conversations may have been due to parent variables, including inadequate knowledge of communication strategies, difficulty dealing with emotions, and a desire to protect the child from the pain of separation; or HCP variables, including variability in the knowledge of the disease trajectory (Bell et al., 2010). When EOL discussions occurred more often and earlier (more than 30 days from the child's death), parents reported feeling more prepared during the child's last month of life (Wolfe et al., 2008).

Decision Making. Six studies focused on evaluating the process of EOL decisions and decision making using qualitative, quantitative, or mixed methods designs (Edwards et al., 2008; Hinds, Drew, et al., 2005; Hinds et al., 2009; Maurer et al., 2010; Pousset et al., 2009; Tomlinson et al., 2011). Four studies used parent-report (Edwards et al., 2008; Hinds et al., 2009; Maurer et al., 2010; Tomlinson et al., 2011), and 2 studies explored the child's perspective related to EOL decision making (Hinds, Drew, et al., 2005; Pousset et al., 2009). Parent perspectives often involved decisions of choosing cancer-directed therapy, do not resuscitate, or terminal care. Common decision factors across EOL choices included medical facts, doing the best thing for the child, and the opinions of others (Hinds et al., 2009; Maurer et al., 2010). However, factors influencing decisions to continue cancer-directed therapy or EOL care differed. The concept of quality of life and the child's wishes were the most frequently reported factors for parents who chose terminal care in comparison with needing to continue cancer-directed therapy as the prevailing factor for parents who chose additional cancer therapy (Maurer et al., 2010). When both parents focused on decreasing the suffering experienced by the child during EOL, they were slightly more likely to report retrospectively that the child suffered less (Edwards et al., 2008).

During EOL, there may be situations where parents are not in agreement on the type of care they wish for their child. In parents with conflicting EOL goals for their child, preliminary qualitative studies found their definition of what it means to be a good parent to their child was constant across EOL trajectories (Maurer et al., 2010). The concept of a good parent was described as

doing right by making informed and unselfish decisions in the best interests of the child, being present at the child's side, teaching the child to make good decisions, advocating for the child to HCPs, and promoting the child's health (Maurer et al., 2010, and Hinds et al., 2009). Four clinician behaviors were identified that support the feeling of being a good parent: (a) HCPs telling parents they are "good parents," (b) not forgetting the child and family once the child has died, (c) providing more support options, and (d) providing coordinated EOL care (Hinds et al., 2009).

In the literature reviewed, adolescents considered different factors compared with their parents when making care-related decisions. They were able to negotiate complex decision processes during which they considered more than one factor at a time and were able to integrate all factors into a final decision (Hinds, Drew, et al., 2005). Furthermore, factors most frequently identified by adolescents as important to their EOL decision included caring about others, avoiding adverse events, and wanting no more therapy (Hinds, Drew, et al., 2005; Jankovic et al., 2008)

Child and Parent Outcomes of Care. Only 2 studies included in this review focused on outcomes associated with EOL care (Kreicbergs et al., 2005; McCarthy et al., 2010). In the study by McCarthy et al. (2010), 41% of parents ($n = 58$) who had a child die a cancer-related death met diagnostic criteria for grief-related separation distress and 22% had clinically significant depressive symptoms. Furthermore, parental perceptions of the child's quality of life during the last month of life, preparedness for the death, and economic hardship were found to predict grief and depression outcomes (McCarthy et al., 2010). Related to symptom management during EOL, Kreicbergs et al. (2005) found 57% of parents ($n = 449$) who had a child with unrelieved pain at EOL were still affected by that experience 4 to 9 years after the child's death. These findings suggest interventions aimed at supporting the child and parent during EOL may moderately affect short- and long-term outcomes. More research is needed to increase our understanding of the impact of the EOL experience on the parent and other family members (eg, siblings, grandparents), individual and family health, and associated health-care costs.

Discussion

The findings of this review identified the importance of symptom management and communication during EOL. Preventing and managing symptoms and assisting the dying child or their family in finding comfort and meaning during EOL are important goals of EOL care (Nuss et al., 2005). Prevalence of symptoms experienced during

EOL does not necessarily provide information regarding the level of distress the symptoms cause the child or parent. Additionally, evidence demonstrates that the presence or type of symptoms reported by parents in the last week of their child's life does not inevitably predict the level of parental concern (Hendricks-Ferguson, 2008; Pritchard et al., 2010). This evidence suggests that the number of symptoms experienced by children who die a cancer-related death should motivate clinicians to query parents about the child's current symptoms of most concern and prioritize these symptoms for interventions, including the provision of anticipatory guidance (Pritchard et al., 2010). Furthermore, unrelieved child or parental distress has been found to be a contributing factor for parents reporting symptoms as concerning, distress, and decreased satisfaction with care at EOL (Kars, Grypdonck, & van Delden, 2011; Mack et al., 2005; Pritchard et al., 2008; Pritchard et al., 2010).

The review indicated that children experience distressing symptoms at EOL despite access to HCPs experienced with EOL care, advanced technology, and availability of numerous agents to alleviate symptoms (Houlahan et al., 2006). Symptom clusters are present in dying children and adolescents, but the exact composition, nature of the clusters, and which symptoms are most distressing to dying children and their families are unknown (Hinds et al., 2004; Mack et al., 2005). Strategies shown to be supportive to parents while the child is experiencing distressing symptoms include pharmacologic and nonpharmacologic interventions, nurse presence with the child and family, providing competent EOL care, and providing anticipatory guidance (Hendricks-Ferguson, 2008; Pritchard et al., 2008; Pritchard et al., 2010). Open communication and access to their child's provider throughout EOL may contribute to positive parental satisfaction with their dying child's symptom experience (Hendricks-Ferguson, 2008; Pritchard et al., 2010; Wolfe et al., 2000; Zhukovsky et al., 2009). However, the literature lacks recommendations for a strategies aimed at managing specific symptoms (eg, pain) or cluster of symptoms.

There is a need to expand the knowledge base regarding interventions aimed at managing all types of symptoms experienced at EOL, not just limiting the knowledge to the study of pain. For example, knowledge of symptom differences related to the child's age and developmental responses is limited, resulting in an absence of evidence to guide appropriate symptom interventions. Furthermore, it is equally important to understand the child and parent perspectives of symptom management interventions. Following implementation of intervention strategies addressing symptoms during EOL, HCPs must evaluate the effectiveness of those strategies.

The timing of EOL discussions is an important factor for HCPs to consider. Often the child's diagnosis or disease status will provide information to guide timing of conversations with the child and parent. Whenever possible, EOL conversations should be initiated early in the disease trajectory. Early EOL discussions are essential to identify what components of EOL care are most important to the child and family and to allow sufficient time to enact plans that support the child's and parents' wishes. However, there may be situations where early EOL discussions may not be feasible because of unexpected clinical changes or respect for a parent's wish not to communicate openly with the child about EOL. Therefore, HCPs should consider the child's expected disease trajectory soon after diagnosis to provide guidance on timing of initial EOL discussions. Interventions aimed at supporting dialogue between HCPs, children, and parents may influence overall patterns of care.

As a standard of care, EOL decisions should involve both parents, HCPs, and the child, when appropriate. Yet a standardized approach for when and how to include the child in EOL decision making is lacking. This review suggested that creating opportunities for parents to work through EOL goals together may lead to improvements in the overall EOL experience of the child (Edwards et al., 2008). Agreement among all involved in the decision-making process is essential in setting and determining a plan to meet EOL goals.

Quality Assessment of the Review

A number of methodological issues were identified in the synthesis of literature on child and parent experience during EOL. Limitations included small sample sizes, suboptimal representation across genders and ethnicities, single-site, retrospective designs, and use of parent-report and medical records as data sources without the collection of concurrent data from the child. Furthermore, more than 30% of the studies were conducted outside the United States where there may be variability in health care delivery systems and EOL services, and thus, different parent or child experiences of EOL care. The EOL experience for children and their parents is an emerging phenomenon predominated by descriptive or observational studies. The resulting level of evidence associated with the majority of studies limits the strength of recommendations related to future research and clinical practice.

Implications for Future Research

In the report *Approaching Death: Improving Care at the EOL*, the Institute of Medicine (1998) made several recommendations aimed at addressing the current shortcomings in EOL care in the United States, including the need

to define and implement priorities at a national level for strengthening the knowledge base for EOL care. In order to address gaps in EOL, knowledge research is needed in the areas of pediatric palliative care, regulation and reimbursement of EOL services, development of validated instruments addressing the complexity of EOL, and development of informatics tools to facilitate the integration and analysis of data from EOL studies (American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care, 2000; NINR, 2011).

What is clear from the review related to the child and parent experience during EOL in pediatric oncology is that there is an initial understanding of (a) types of symptoms children experience when dying a cancer-related death, (b) types of interventions used to manage pain during EOL, (c) patterns of care children experience, (d) types of decisions that need to be discussed general to pediatrics and EOL and specific to children with cancer, and (e) preliminary outcomes of bereaved parents following the death of a child.

A thorough understanding of the child's perspective related to each theme and how the pediatric oncology nurse may affect the child and parent experience is unknown. In response to limited valid and reliable instruments to measure concepts within each theme, there is an opportunity to leverage both quantitative and qualitative methods to seek knowledge of the child and parent experience during the transition from curative-focused therapy to PC and EOL. Furthermore, exploring the experiences of nurses and other HCPs during PC and EOL may enhance the knowledge foundation related to the experiences of children and parents from a different perspective.

Another area for investigation includes the development and testing of a conceptual framework. The majority of studies lacked a theoretical underpinning, an omission that may provide challenges as the state of the science progresses. Kane, Hellsten, and Coldsmith (2004) propose

pediatric EOL care research also include testing and refining theories that account for the association of social and spiritual relationships and the relief of suffering . . . in order to develop interventions designed to minimize suffering and improve the quality of life for children dying from serious illnesses and their families. (p. 181)

An established conceptual framework will equip researchers to describe the core concepts of EOL care and how they interact with one another to achieve a particular outcome.

There is a clear need to develop and test instruments in a variety of countries and languages to prospectively measure symptoms, quality of life, communication, and decision making in the pediatric oncology population. Despite

the availability of reliable tools to measure quality of life in pediatric oncology patients, there is an absence of tools which adequately measure quality of life within the context of EOL (Hinds, Burghen, Haase, & Phillips, 2006).

Limitations related to sample characteristics across studies were identified as a critical gap in this review. Specifically, studies did not reflect optimal representations across ethnicities and race. It is important that future studies allow opportunities for participants representing both genders and a variety of race and ethnicities across the globe, which may be accomplished through multisite or cooperative research. Moreover, there is limited research on EOL specific to pediatric oncology compared with the adult population. Replication studies are needed to enhance reliability and generalizability of findings to other pediatric oncology settings. In addition to replicating descriptive designs, there is a clear need for intervention research to support areas identified in the literature, including symptom management, patterns of care, and decision making. Areas of focus include assessment, interventions, and outcomes of individual symptoms and symptom clusters. Development and implementation of a bundle of activities aimed at managing symptoms may provide consistency and applicability of symptom management strategies to the clinical setting. Intervention research will allow investigators to advance the state of the science related to the child and parent experience during PC and EOL. Finally, it is unclear what role other factors might play in facilitating or limiting quality care related to each of the themes.

The majority of available literature creating knowledge about EOL for children and adolescents with cancer is based primarily on medical record reviews and to a lesser extent, staff and parent observations (Hinds, Burghen, & Pritchard, 2007). Nurse researchers who have paved the path in pediatric PC/EOL research have identified several challenges to conducting this type of research, including a negative risk/benefit ratio as perceived by local institutional review boards (IRBs), parent refusal rate limiting generalizability of findings, and limited availability of measures tested in dying children (Nuss et al., 2005). Hinds et al. (2007) suggested possible reasons for a lack of patient-reported outcomes in pediatric oncology at EOL including hesitation of the clinician to directly and formally solicit patient-reported preferences and outcomes due to concerns about offending the already emotionally burdened family. Additionally, researchers may experience concern about obtaining IRB approval due to the perceived potential emotional distress of interviewing children or parents. These perceptions may be a barrier to obtaining IRB approval for studies involving children and adolescents during EOL. Further resistance from members of the health care team are based on the belief that interviews may cause parents

additional stress resulting in the transition of their child to a different institution. Through intra- and interprofessional collaboration, nurse researchers may anticipate these barriers and develop research questions aimed at current limitations.

Implications for Nursing Practice

A clear understanding of EOL care has implications for clinical practice across a variety of disciplines. EOL care is complex; disciplines, assessments, interventions, and outcomes must be strategically aligned to provide quality and comprehensive holistic care. Standardized guidelines directing HCPs to provide quality EOL care are needed. However, standardization must be balanced with individualization as patient and family values and preferences are core attributes for EOL care. Interprofessional teams need skills and tools to appropriately assess these values during EOL in order to achieve patient and family goals and a peaceful death.

Globally, the profession of nursing is engaged in every level of symptom management, including assessment, planning, delivery of interventions, and evaluation. Nurses provide a unique perspective to manage symptoms at EOL in pediatrics. The nature of the nurse's clinical care role allows for frequent interaction and relationship building with the child and parents. For instance, nurses are uniquely positioned to be an advocate for patients and family members by fostering timely and clear communication with the health care team. In order to support a child or adolescent and the family, there must be a trusting relationship between the child, parent, and care team (Pearson, 2010). Nurses support and preserve the parent-child relationship and facilitate the parental presence for the child during EOL (Kars, Grypdonck, & van Delden, 2011). Pediatric nursing care should be holistic, encompassing not only the physical illness but also the child's mental, emotional, developmental, and spiritual needs (Pearson, 2010). Reflection on personal practice and previous clinical situations is essential for clinicians to be able to enhance their care of future patients (Pritchard & Davies, 2002). Through reflection, nurses may identify questions useful for guiding clinical interventions and research.

Communication is central to the child and parent experience and is a defining attribute of EOL care supportive in the achievement of other core elements, such as provision of interprofessional care across the continuum, joint decision making, and provision of anticipatory guidance. There is continued support to improve interprofessional communication in complex health care settings. In addition to communication, there is an increasing need to educate and reinforce with HCPs the core principles of therapeutic and effective communication (eg, listening). Goal setting and

identification of child and parent preferences would not be possible without effective communication. Parental ratings of quality of care increased when there were opportunities to address issues related to goals of care, potential outcomes related to changing and deteriorating clinical status of the child, and affirmation of ongoing open and honest communication (Ullrich et al., 2010).

In order to identify appropriate interventions for children with cancer at EOL, HCPs must seek a partnership with the child and their family. Stillion and Papadatou (2002) suggest the following 5 major variables HCPs should take into account whenever they seek to meet the needs of children who are terminally ill: (a) personality, (b) life experiences (especially those related to illness, death, and loss), (c) patterns of communication within the child's immediate surroundings, (d) availability and quality of support, and (e) developmental level. Developmental level is critical in determining interventions as well as gauging communication about EOL care and achieving a quality symptom assessment (subjective and objective). Furthermore, the interaction of these variables determines how children are likely to perceive, cope, and make sense of their illness and impending death (Stillion & Papadatou, 2002). Partnering with children, adolescents, and their families allows the HCP to build trust and identify appropriate interventions for individual situations.

In addition to enhancing communication during EOL, there is a general need to improve access to PC/EOL education for HCPs. Although education in this area is improving, with many countries leading the way, studies conducted in the United States continue to document educational deficiencies among physicians and nurses (Helft, Chamness, Terry, & Uhrich, 2011; Truog et al., 2008). EOL is experienced in a variety of settings and environments, fueling a need to make education standard for health care professions. Methods that have been shown to improve the application of PC principles include education, training, and research (Grant, Elk, Ferrell, Morrison, & von Gunten, 2009). Education which facilitates attitudinal and cultural changes among HCPs needs to be accompanied by support systems so that an actual change in behavior occurs as a result of educational interventions (Pierce, 1999). The development of training programs such as Education for Physicians on End of Life Care, End of Life Nursing Education Consortium within the United States, and curricula developed for internal medicine residency programs create a structure that allows health care organizations to support the education needs of HCPs (Truog et al., 2008).

Limitations

An important limitation of the review is the possibility that some studies related to each theme did not make the

initial or final pool of articles for evaluation due to the use of different search terms or the presence of other exclusion criteria. Therefore, thematic summaries of the evidence should be interpreted with caution.

Conclusion

Based on a review of current literature related to EOL experience of children who die a cancer-related death and their families, several conclusions may be drawn. First, EOL care is complex with elements that require individual and team assessment. Second, there is literature to support the presence of distressing symptoms experienced by children during EOL. The literature indicates that frequency and distress are not synonymous but stops short of identifying what makes symptoms distressing to children and what interventions are effective in managing the symptoms. Third, assessment of children and parents' perception of EOL care is critical in identifying phenomena that require future interprofessional research. Fourth, the decision-making process and communication influence EOL patterns of care. The development and testing of interventions may support the standardization of care delivered to children and their families at EOL. Nurses have the opportunity to assess and meet the needs of children and their parents during all phases of EOL, whether they are physiological, emotional, or psychosocial in nature.

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