

Palliative nursing care for children and adolescents with cancer

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Abstract: Pediatric palliative care aims to enhance life and decrease suffering of children and adolescents living with life-threatening conditions and their loved ones. Oncology nurses are instrumental in providing palliative care to pediatric oncology populations. This paper describes pediatric palliative care and provides an overview of literature related to the physical, psychological, social, and spiritual domains of palliative nursing care for children and adolescents with cancer. Nurses can provide optimal palliative care by accounting for children's understanding of death, encouraging early initiation of palliative care services, and improving utilization of pediatric palliative care in cancer settings. Specific roles of registered nurses and advanced practice nurses in pediatric palliative care will be addressed. Recommendations for future research are made to further advance the science of pediatric palliative care and decrease suffering for children and teens with cancer.

Keywords: pediatric palliative care, pediatric cancer, oncology, child, suffering

The death of a child is a "unique tragedy."¹ Unfortunately, a staggering 53,000 children die annually in the United States.² Of these, cancer is the most common cause of death from disease, with over 2000 children dying of cancer in 2007.³ Children living with cancer may endure substantial suffering.⁴⁻⁶ Initiatives to improve quality of life and decrease suffering in pediatric oncology patients and their loved ones are represented by the integration of palliative care teams within pediatric oncology settings in the United States⁷ and diverse geographic locations such as Lebanon,⁸ Israel,⁹ United Kingdom,¹⁰ Italy,¹¹ Germany,¹² and Malaysia.¹³ This paper aims to: (1) describe pediatric palliative care and its use within the pediatric oncology population; (2) provide an overview of literature related to the physical, psychological, social, and spiritual domains of palliative nursing care for children and adolescents with cancer; (3) discuss challenges in pediatric palliative care in pediatric oncology; and (4) offer recommendations for nursing practice and research.

Pediatric palliative care

Palliative care received recognition as a specialty area after receiving its own definition published by the World Health Organization in 1990.¹⁴ According to The Center to Advance Palliative Care,¹⁵ palliative care (1) provides patients with relief from the symptoms, pain, and stress of serious illness; (2) aims to improve quality of life for both the patient and their family; (3) includes a multidisciplinary team of doctors, nurses, and other clinicians who work together with patients' other providers to offer an extra layer of support; (4) is appropriate at any age and at any stage in a serious illness;

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and (5) can coexist with curative treatment or end-of-life care. Palliative care for children is specifically defined by the National Hospice and Palliative Care Organization as “a philosophy and an organized method for delivering competent, compassionate, and consistent care to children with chronic, complex and/or life-threatening conditions and their families.”¹⁶

The goal of pediatric palliative care is to enhance life, relieve suffering, optimize function, and provide personal growth opportunities for children with life-threatening conditions, such as cancer, and their family members.¹⁶ A holistic family-centered model of pediatric palliative care encourages families’ involvement in a mutually beneficial and supportive partnership.¹⁷ In focusing on a holistic approach, this paper is organized according to the four domains emerging from the definitions of pediatric palliative care:^{15,16} physical, psychological, social, and spiritual. Each domain of pediatric palliative care will be described, followed by an overview of recent research specific to pediatric oncology. Databases including CINAHL, PsycINFO, Medline, and PUBMED were used to locate the most recent studies within 2002–2012. Keywords included pediatric, oncology, cancer, child, and palliative care. Additional terms were added to locate studies specific to each dimension (eg, “pain” for search related to the physical dimension, “spiritual” for search related to the spirituality dimension).

Overview of literature

Physical domain of pediatric palliative care

The physical dimension of pediatric palliative care involves management of pain and symptoms and should be a cornerstone of care for children facing cancer.¹⁸ Patients present with symptoms related to diagnosis, disease stage, and therapeutic interventions.¹⁹ Symptoms change in response to primary and palliative treatments and frequently require re-evaluating the child’s condition and needs. Pharmacologic and nonpharmacologic treatments for pain, dyspnea, nausea and vomiting, increased secretions, and seizures can be required.¹⁸ The importance of providing timely management of pain and symptoms is well recognized in palliative care. Although the integration of pediatric palliative care programs have shown a decrease in the suffering perceived by children with cancer,²⁰ symptom distress remains prevalent in children and teens dying from cancer.

Fatigue, pain, dyspnea, nausea, and anorexia have been reported as the most common physical symptoms experienced by children with cancer.^{8,20,21} Bereaved parents have reported that fatigue, pain, changes in appearance and

behavior, and breathing changes were the most concerning cancer-related symptoms during their child’s last days of life.⁵ The most common symptoms are not always the most severe or distressing to pediatric oncology patients.²¹

Some studies have reported that fatigue was decreased in 10–18-year-olds undergoing myelosuppressive chemotherapy²² and in 10 to 17-year-olds who were hospitalized over 5 days.²¹ Other adolescents (10–19 years of age) with cancer have reported more frequent symptoms of fatigue over the course of chemotherapy.²³ Fatigue has been associated with increased anxiety, sadness, and fear at the end of life but remains an underreported and undertreated symptom in pediatric oncology patients.²⁴

Initiatives on pain and symptom management in pediatric oncology have been developed in response to the unrelieved moderate to severe pain experienced by children.^{25,26} These programs included provider education and guidelines for improved pain assessment and management in pediatric oncology. Studies have examined pharmacological strategies to provide optimal pain relief for children with advanced cancer.^{27,28} Research also suggests that nonpharmacological strategies (eg, music therapy, creative arts) may decrease pain in children with cancer.^{29,30}

Nausea and vomiting is another prevalent and distressing symptom experienced by children and adolescents with cancer, often associated with hospitalizations or chemotherapy. Adolescents with cancer have reported that nausea remained present over a 5-day hospitalization.²¹ Other adolescents perceived that nausea became more distressing over the course of chemotherapy.²³ Nausea and vomiting are often dependent on chemotherapy agents used. Common chemotherapy agents with high emetic potential include cisplatin, cyclophosphamide (dose > 10 mg/kg), and cytarabine (dose > 1 g/m²), while other agents have moderate emetic potential (eg, carboplatin, ifosfamide, methotrexate > 1 g/m²).³¹ Younger children often depend on their primary caregiver to assess and communicate their physical symptoms. A recent study reported that 7–12-year-old children with cancer experienced increased nausea and vomiting throughout chemotherapy;³² this study also found positive associations among patient, parent, and nurse reports on chemotherapy-induced nausea and vomiting, except for patient and nurse reports on anticipatory nausea.³²

Ullrich and colleagues²⁴ have found positive associations among nausea, vomiting, and fatigue in children with cancer near the end of life, and thus increased suffering. The multidimensional nature of symptoms is noted across studies,

which compounds symptom management, particularly as cancer progresses. Recommendations exist to improve symptom management in pediatric oncology patients, yet needs for better assessment, measurement, documentation, and treatment of many physical symptoms still remain.^{25,32,33}

Psychological

The psychological dimension of pediatric palliative care for a child or adolescent with cancer affects how the child feels about himself or herself, coping mechanisms, overall perception of quality of life, and the grief and emotions associated with a life-threatening diagnosis.^{19,34,35} Children may have thoughts about death that often appear in their fantasies and in their play.³⁶ The palliative care team can provide developmentally appropriate support to help children with cancer process feelings related to their illness, or in some cases, the possibility of death.

Psychological symptoms reported in children and adolescents living with an advanced disease include depression, sadness, anxiety, nervousness, worry, guilt, loneliness, and fear.^{20,35,37} The threat or possibility that death may occur is prevalent along the cancer trajectory. In a recent study of 98 children (7–15 years old) newly diagnosed with cancer, emotional distress was manifested in descriptions of sadness, anxiety, worry about death, anxiety about academic performance, loss of self-control, and uncertainty around prognostic discussions.³⁴ Implementing palliative care services for all pediatric cancer patients can allow fears, worries, or concerns about death to be cognitively framed within the context of the current prognosis and plan of care.

Nurses' understanding of the psychological aspects of childhood cancer has increased substantially in the past 30 years, giving way to psychological interventions aimed at reducing psychological distress (eg, anxiety, depression) and improving coping and psychological adjustment (eg, problem-solving skills, perceived competence, educational functioning).^{38–42} However, patient reported outcomes (eg, directly from pediatric oncology patients) at end of life are sparse.⁴³ Interventions that address emotions, grief, and death-related fears are very much needed in this population. Children, adolescents, and their families deal with a myriad of stressors from the time of diagnosis to survivorship or end of life and bereavement. Gaps still remain in understanding the spectrum of emotions children with life-threatening conditions are experiencing, and the coping mechanisms involved throughout the course of illness. More research is needed to allow nurses to better anticipate and respond to

significant psychological challenges faced by children and adolescents with cancer who are dying.

Social

The social dimension of pediatric palliative care is another important element to address in enhancing quality of life for the child with cancer while supporting the family. Social aspects involve the child's interactions with or isolation from others, practical realities, and social implications for the family.^{44–48} Research focused on social implications for family members after a child's death show profound and long-lasting results.^{49,50}

Social support for children with life-threatening conditions may emerge via social networks or other means of ongoing interactions with other children with similar conditions, family members, or other adults who play significant roles in their lives.⁵¹ Evidence suggests that social interaction, but also having time alone, can result in positive coping outcomes for hospitalized children with cancer.⁵² Teens with cancer have perceived that support groups provided opportunities to interact with other ill peers, give and receive inspiration, and be a normal teenager.⁵³ Support by healthy friends is more often limited, as studies have rarely explored how children can communicate or lend their support to a peer with cancer. Questions about whether or not to have conversations with dying children about their prognosis have led to enlightening research which supports the difficult dialogue.⁵⁴

Armstrong-Dailey and Zarbock³⁶ believe in the importance of a seriously ill child living to the fullest, and not just existing. A child living with a life-threatening condition such as cancer is still a child and benefits from continuing familiar activities and interactions for as long as possible. Children often express the need to maintain some control over their illness and treatment. Children may want to be involved in their care decisions and wish fulfillment.^{51,55} Daily activities such as going to school, having responsibilities, being disciplined, and spending time with friends and family serve to extend normalcy and the very core of life itself.¹⁸

During treatment, health care providers may recognize families' sources of strength and may be helpful in building on those supports and resources.⁵⁶ Bereaved parents are at risk for psychological and even physiologic distress after a child's death.⁵⁷ Studies in Scandinavia report increased risk for psychiatric hospitalization and higher levels of distress and psychologic morbidity in bereaved compared with nonbereaved parents.^{54,58} Bereaved siblings have been found to have high levels of stress and adjustment difficulties⁵⁹ or may experience positive change after the death of a brother or sister.⁶⁰ The

attention and care dedicated to the dying child becomes a part of the long-lasting effect on bereaved survivors.⁶¹ Parents have shared that they felt sibling support groups and bereavement follow-up was lacking and sorely needed.^{62,63}

Spiritual

The spiritual dimension of pediatric palliative care refers to how the child understands the meaning of an experience.¹⁹ Spirituality comes into focus when an individual faces emotional stress, physical illness, or death.⁶⁴ Questions such as “Why is God doing this?” or “What is heaven like?” may be asked.³⁶ In childhood, spirituality is developmentally defined and can be experienced without any personal religious beliefs, values, and practices.¹⁸ Spirituality is involved with a child’s approach to understanding life and includes concerns such as unconditional love, forgiveness, hope, safety, security, and legacy. Even very young children may need to engage in discussions related to what dying and the afterlife are like.³⁶

More than a decade ago, studies documented that children living with life-threatening illnesses exhibit thoughts and feelings about prayer and God.⁶⁵ Recent studies have suggested that many children and teens with cancer receive comfort from hope and faith in God or a higher power, praying, or reading the Bible.^{33,66,67} Prayer or spiritual healing has been used by relapsed cancer patients aged 0–25 years of age to cure, prevent, or slow the progression of cancer and improve their overall health and wellbeing;⁶⁸ the majority ($n = 15$, 68%) of those patients perceived prayer or spiritual healing was effective.

While some children and teens perceive positive outcomes such as improved comfort and health related to their spirituality, they sometimes struggle to find meaning and purpose in their lives.^{33,67} Their spiritual perspectives may parallel the ups and downs of their illness.^{69,70} Children with

cancer may have spiritual concerns related to legacy to affirm life’s purpose and meaning. Bereaved parents and siblings of children who died of cancer⁷¹ and providers⁷² have reported that some children with cancer created legacies before they died as they anticipated or prepared for their impending deaths. While legacy-making has been tested in adults,^{73–77} the effects of legacy-making activities on children’s spirituality have rarely been tested in oncology or palliative care populations. Although research has made strides to further health care providers’ knowledge on spirituality in palliative care, more research is needed about the spiritual needs of pediatric patients who are suffering and dying from cancer and the interventions that may reduce spiritual suffering or promote spiritual wellbeing.

Implications for practice

Gaps in managing the physical, psychological, social, and spiritual domains support the need for pediatric palliative care in cancer populations. However, challenges in pediatric palliative care exist, such as accounting for children’s understanding of death, encouraging early initiation of palliative care which includes end of life discussions, and improving utilization of pediatric palliative care. Nursing implications for each of these practice components will be addressed.

Children’s understanding of death

Necessary to meeting the physical, psychological, social, and spiritual needs of children and adolescents with cancer is an understanding of children’s concepts of death which can be influenced by their developmental level, maturation, and condition. Nurses can help assess children’s verbal and nonverbal cues among the domains of pediatric palliative care to help determine children’s developmental understanding of death (Table 1). Four elements represent a complete developmental understanding of death: irreversibility

Table 1 Examples of children’s developmental understanding of death

	Domains of pediatric palliative care			
	Physical	Psychological	Social	Spiritual
Pre-school	My tummy hurts. Did I do something wrong?	I might die if I go to sleep. I’m scared.	I just want mommy to always stay with me.	I’m going to heaven soon to meet Jesus.
School-age	Chemo makes all your hair fall out.	My dog helps me feel happy.	My brother gets to have all the fun. I never get to see my friends at school anymore.	I’m not afraid of dying, I just don’t know how.
Adolescent	In case something happens, I want to talk to my palliative care team to make sure they know my preferences for pain control and DNR.	I feel lonely. Cancer sucks.	My friends at the hospital are the only ones who understand what it feels like to be dying.	This is not fair – why did God let me get cancer? I’d like to write out a will to divvy out my belongings.

Abbreviation: DNR, do not resuscitate.

(understanding that dead things will not live again), finality (understanding all life-defining functions end at death), universality (understanding all living things die), and causality (realizing what causes death).^{46,78} Children's understanding of death progresses along the continuum from irreversibility to causality as children develop.

Very young children often do not understand the finality of death,⁴⁶ and often interludes of separation from their parents are feared more than a terminal diagnosis. Early childhood is often called the magical years,⁷⁹ which may contribute to young children's beliefs that they caused the illness and resulting distress to their families. School-age and adolescent children are more advanced in their understanding of death, but may be preoccupied with physiological aspects of the dying process as their concerns may focus on body image and function. During Piaget's concrete operational stage of development, school-age children typically begin to understand that death is permanent and universal. Importantly, evidence suggests that children and adolescents who experience a life-threatening illness such as cancer may develop an advanced understanding of death.^{71,80}

Early initiation of pediatric palliative care

Pediatric palliative care is often initiated late in the course of illness for children and adolescents with cancer. A recent study reported that children with cancer at a Canadian hospital were referred 461 days, on average, after diagnosis to palliative care.⁸¹ A multicenter study including six hospital-based pediatric palliative care programs in the United States and Canada reported a median time of 107 days from initial consult to death.⁸² However, about 20% of referred patients had cancer. Results showed that these pediatric oncology patients (as well as those with cardiovascular conditions) were more likely to die within 30 days of initial consult than other diagnoses.

Though pediatric oncology patients (10–20 years of age) have participated in complex end-of-life decisions based on their personal preferences and the needs of others,⁶¹ end-of-life discussions among providers, children with cancer, and their family members often occur very near the time of a child's death. Drake, Frost, and Collins³⁷ found 58% of the parents whose child died in the hospital were approached about whether or not to initiate a do not resuscitate (DNR) status on the last day of their child's life.³⁷ In a study of 77 terminally or chronically ill children, the median time from a DNR decision to death was less than 24 hours.⁸³ Physicians have initiated discussions about death with dying adolescents or their families an average of 30 days before death.⁸⁴ Initial discussions were more likely

to occur in the last week of life in adolescents with leukemia/lymphoma than those with central nervous system tumors or solid tumors. Conversations initiated early in the illness trajectory do not always need to focus on the possibility of death but may communicate to the child that a door is open for discussions about prognosis. Health care providers who project availability to respond to children's questions openly and candidly offer needed support to children and their families. Late communication can leave very little time to prepare for death.

Nurses caring for oncology patients have the unique opportunity to improve timing of pediatric palliative care services. Nurses can be a liaison between the pediatric patient and family, medical team, and the pediatric palliative care team to overcome the challenges that may interfere with optimal patient care. While children and adolescents with cancer often are treated in an acute-care medical model focusing on curative treatments,^{85–87} nurses can promote the introduction of palliative care early in the illness trajectory. Pediatric palliative care should ideally begin when a child is diagnosed with a potentially life-threatening condition, such as cancer,⁸⁸ and continue throughout curative therapy or end of life. Early incorporation of a pediatric palliative care team can build relationship and trust among the primary oncology team, pediatric palliative care team, child with cancer, and his or her family members.

Involving children or adolescents in developmentally appropriate discussions may provide clarity for how he or she wishes to live the remainder of life. The nurse is in a key position to include the child patient, a vital member of the pediatric palliative care team, in health care team interactions. Children's interactions with others are often dependent on their developmental level as well as their level of physical and emotional comfort in interfacing with family members and health care providers. Physical and emotional discomforts often are barriers to open exchange with parents and providers, as a child may become introspective and withdrawn. Child life specialists, social workers, nurses, chaplains, and other members of the interdisciplinary health care team play important roles in opening communication channels.

Utilization of pediatric palliative care

There also is reported underuse of pediatric palliative care teams at pediatric oncology institutions.^{7,20,89} In a retrospective study of 119 pediatric oncology patients who died, the pediatric advanced care team was involved with only 48 patients.²⁰ In another study at a National Cancer

Institute-designated pediatric comprehensive cancer center, 954 patients were seen for malignant disorders in a 9-month period, yet only 15 pediatric patients were referred to the palliative care team.⁸⁹ A recent survey sent to 232 children's oncology group institutions (N = 187, response rate 81%) found only 58% of the institutions reported the availability of a palliative care team, and there was significant variability in the use of the pediatric palliative care team across participating institution sites.⁷ There was a median of 45 newly diagnosed patients (range 0–426 patients) per institution. The palliative care team was used by a median of three patients with a newly diagnosed malignancy (range 0–50), per institution. Additionally, 50% of the patients with a relapsed malignancy did not receive services from the palliative care team. Palliative care interventions (eg, pain management, counseling, support groups, or comfort care) have been documented in only 23% of medical records (N = 460) from pediatric deaths resulting from complex chronic conditions, including cancer.⁸⁶ End-of-life interventions (eg, family counseling around the time of death, memory-making, debriefing, grief management) were noted in only 6% of medical records.

Although pediatric palliative care teams may not be readily available at every pediatric oncology center, nurses across practice levels are in ideal positions to provide palliative care to children and adolescents with cancer and their families (Table 2). Assessment and management of children's palliative care needs are best accomplished by nurses and other health care providers attuned to physical,

psychological, social, and spiritual realities. Nurses can carefully appraise the child and family's developmental level, the child's physical discomfort level, presence of emotional pain, communication channels, and practicalities such as finances and care setting.

Studies have focused on education for nurses and other clinicians who provide cancer and palliative care for children.^{90–92} Pediatric palliative care nurses, especially nurse practitioners who are leaders among nursing communities, need to take reign of leadership roles in nursing practice, teaching, research, and service. Because pediatric palliative care is a relatively new specialty, there is a significant need for nurse practitioners to educate patients, families, and other providers on the fundamental principles of pediatric palliative care as well as characteristics of an appropriate consult.⁹³ The nurse can educate other providers by participation in hospital nursing orientations and continued medical education opportunities. Nurses may debrief with primary care teams after a difficult case or assist with bereavement services within the hospital.

Palliative care nursing roles in pediatric oncology can be emotionally challenging. When caring for children with cancer, nurses may be confronted with the physical and emotional suffering of children and families. Support for nurses can include adequate education, debriefing opportunities, and excellent coping skills. Optimizing the team provides stability for the nurse as he or she may rely on team members for support. If supported through education, self-care, and an interdisciplinary team, the nurse will likely find a rewarding career in pediatric palliative care that promotes professional and personal growth.

Table 2 Palliative nursing roles in pediatric oncology

Registered nurse	Palliative care NP
Assess patient and family's physical, psychological, social, and spiritual needs	Provide comprehensive medical and psychological evaluation
Assess effectiveness of plan of care, including prescribed medications	Provide skilled and comprehensive symptom management
Support physician or NP in treatment and family education	Formulate palliative care plan; communicate plan to patient, family, and medical team; monitor/modify plan based on needs of child and family
Communicate needs of child and family to medical team	Provide consistent care across settings; assist and support palliative care physician and primary care team
Guide child and family through difficult and sensitive situations (eg, respond to questions and concerns, reaffirm plan of care)	Ensure that patient and family understand plan of care and expected outcomes; educate and guide other providers on fundamental principles of palliative care

Abbreviation: NP, nurse practitioner.

Implications for nursing research

Advances in the science of pediatric palliative care have been made over the last decade. Still, more work is needed to enhance life and decrease suffering for children living with cancer and their families. Patient reported outcomes from pediatric oncology patients at end of life are sparse.⁴³ Despite logistical research challenges of obtaining child self-reports (eg, human subject protections of child participants, required child assent and parent consent, recruitment of ill children), researchers must take the necessary steps to include the child's voice in study methods so that we can better understand cancer and dying from the child's perspective. To accomplish this, more child measures specific to palliative care need to be developed and validated. Prospective and longitudinal research is necessary to examine similarities and differences in these patient reported outcomes over

time. Now is the time to move descriptive evidence towards intervention studies to address emotions, grief, and death-related fears in pediatric palliative care populations early in the illness trajectory.

Researchers need to collaborate with institutional review boards to ensure optimal methods for protecting child participants remain in place but without unnecessary patient and parent burden to potential participants. Scientists must consider more innovative recruitment methods, such as social media or other technology-driven strategies, to overcome potential barriers of low enrollment, which can be detrimental to pediatric palliative care studies.

Strategies to include low income and minority participants should be woven into grant applications to increase the diversity of research study samples. For example, rather than requiring a participant to have a computer with internet access for a technology-driven study, the research team could budget for several smart phones to loan to participants who could not otherwise participate. Establishing and maintaining relationships with international experts and leaders in pediatric cancer and palliative care (eg, via conference networking or involvement in global medical initiatives) can lead to collaborations that would provide additional cultural layers to the current state of knowledge in pediatric palliative care for children with cancer and their families.

Conclusion

To share the tumultuous journey of cancer and end of life with a child or adolescent is a challenging role yet one of the greatest honors obtainable. In the midst of patient and family suffering across physical, psychosocial, and spiritual dimensions, nurses witness joy and gratitude that seems to be mysteriously gifted to many children with cancer and their families. We challenge nurses to become local, regional, and national leaders in palliative care practice, research, teaching, and service. It is only then that we will shift the paradigm of palliative nursing care to the highest level and offer the best-deserved care to the exceptional children and adolescents facing, suffering with, and dying from cancer.

Disclosure

The authors report no conflicts of interest in this work.

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