
PEDIATRIC PALLIATIVE CARE IN CHILDHOOD CANCER NURSING: FROM DIAGNOSIS TO CURE OR END OF LIFE

TERRAH L. FOSTER, DEBORAH A. LAFOND, CHERYL REGGIO, AND PAMELA S. HINDS

OBJECTIVES: *To describe selected components of pediatric palliative care from diagnosis to cure or end of life that combine to help nurses and other clinicians achieve goals of care for children with cancer and their families.*

DATA SOURCES: *Published articles.*

CONCLUSION: *Pediatric palliative care is characterized by diversity of care delivery models; effect of cancer on the family as the central focus of care; and consideration of culture, spirituality, communication, and ethical standards. End-of-life issues that can be anticipated by nurses and other clinicians include symptoms of cancer or its treatment, the importance of hopefulness, the relevance of trying to be a good parent in decision making, the meaning of legacy making of ill children, and family bereavement.*

IMPLICATIONS FOR NURSING PRACTICE: *Direct nursing care strategies to achieve pediatric palliative care goals are vital to reduce child and family suffering from cancer.*

KEY WORDS: *Pediatric palliative care, pediatric oncology, nursing care, family.*

Terrah L. Foster, PhD, RN, CPNP: Assistant Professor, School of Nursing, Vanderbilt University, Nashville, TN. Deborah A. Lafond, MS, PNP-BC, CPON: Nurse Practitioner, Neuro-Oncology and PANDA Care Team, Department of Hematology/Oncology, Children's National Medical Center, Washington, DC. Cheryl Reggio, BN-PC, RN, OCN®, CPON: Nurse, Hematology/Oncology, Blood and Marrow Transplant, Children's National Medical Center, Washington, DC. Pamela S. Hinds, PhD, RN, FAAN: Director, Department of Nursing

Research and Quality Outcomes, Children's National Medical Center, Professor of Pediatrics, The George Washington University, Washington, DC.

Address correspondence to Terrah L. Foster, PhD, RN, CPNP, Vanderbilt School of Nursing, 461 21st Avenue South, 409 Godchaux Hall, Nashville, TN 37240. e-mail: terrah.L.foster@vanderbilt.edu

© 2010 Elsevier Inc. All rights reserved.

0749-2081/2604-832.00/0.

doi:10.1016/j.soncn.2010.08.003

THE PURPOSE of pediatric palliative care (PPC) in oncology is to deliver competent, compassionate, and consistent care to children living with cancer and their family members.¹ Pediatric palliative cancer care includes physical, psychological, educational, social, and spiritual goals and is provided concurrently with disease-modifying therapies or as the main goal of care. This care aims to enhance life, decrease suffering, optimize function, and provide opportunities for personal and spiritual growth. Interdisciplinary palliative care includes the child, family, and caregivers from the time of the cancer diagnosis, continuing throughout all cancer treatments into survivorship or cure, or until the end of life. The purpose of this article is to describe selected components of PPC that when combined help nurses and other clinicians achieve goals of care for the ill child and the child's family. Particular emphasis is given to the careful selection of a model of care that matches the culture of the care setting; incorporates essential components of PPC (effect on family, cultural considerations, spirituality, communication, ethical standards) and guides strategies to achieve related goals; anticipates end-of-life issues (symptoms of cancer or its treatment, hopefulness, trying to be a good parent in decision making, legacy making); considers bereavement of family members who experience the death of their child, and the effect of PPC care on the nurse.

MODELS OF PEDIATRIC PALLIATIVE CARE

The task of caring for the estimated 50,000 children who die each year in the United States and the more than 500,000 children who are living with life-limiting conditions is daunting.² The growth of PPC programs has significantly increased throughout the United States and internationally since the first programs of the late 1990s.³ The American Academy of Pediatrics⁴ and the Institute of Medicine⁵ call for the integration of palliative care early in the process of life-limiting illnesses. However, these calls to action do not define best practice for models of care.

Several models of care delivery exist (Table 1) to guide the highest quality of care in the face of resource limitations, a shrinking health care economic environment, and the overwhelming needs of patients and families. The models differ by the extent to which a PPC team has

responsibility for direct care (from consultative only to becoming the primary care providers), the location of the team involvement (inpatient, outpatient, home, or hospice), and the flexibility of the care (limited to a single area or moving with the child across care areas). Each of these models has advantages and disadvantages that must be weighed against the benefits to patients and their families, health care staff, and institutions. These models of care are not mutually exclusive and may exist within a single institution or illness trajectory for any given child. Each institution must determine which program will best meet the needs of its patients, families, and health care teams in the context of health care reform initiatives and available resources.

The choice of the care delivery model should be based on a needs assessment and available resources. Nursing plays an integral role in PPC program development and should be at the forefront of needs assessment. The nurse is a main care provider in each of these care delivery models, yet subtle differences in the nursing role may exist, depending on the institution's vision. Several excellent assessment tools are available through the Center to Advance Palliative Care or other sources, such as the Initiative for PPC Institutional Self-Assessment Tool, which can guide reflection of institutional and unit-based issues and policies.^{6,7}

ESSENTIAL COMPONENTS OF PEDIATRIC PALLIATIVE CARE

Effect on the Family

Universal to all delivery models in PPC is care to the seriously ill child, and his or her loved ones. Childhood cancer pervades the life of the entire family unit. Parents, ill children, and siblings have perceived that cancer caused the life of their family to break or fall apart.⁸ Fear, uncertainty, chaos, and loneliness replace what was safe, secure, and well known. Family members have reported that they experience fundamental changes in their daily lives. For example, the child with cancer may not be able to attend school as usual, and parents' work routine is altered. Healthy siblings are often cared for by grandparents or friends and often have to go to the hospital to visit their ill sibling or parents. Siblings sometimes assume caregiving or protective roles of caregiver

or parent.⁹ Family members may experience the full-time work of now caring for the ill child. Days are filled with appointments, procedures, waiting times, and coordinating practical matters associated with the child's disease.⁸ Parents and siblings may feel emotionally torn because their thoughts constantly remain with the ill child, leaving limited energy for other relationships and thereby potentially contributing to problems in family relationships, including relationships within marriage, between siblings, and between the ill child and other family members.

Family members have also reported that childhood cancer introduces a new dependency on others.⁸ Children with cancer are dependent on professional staff and parents for their care. This new dependency may be particularly problematic for adolescents who are striving for independence at the same time that the childhood cancer journey exerts its effect.

Healthy siblings depend on other people (eg, friends, relatives) to take care of them because their parents are now focused on caring for the ill child. Parents turn to staff members to help care for their ill child and look to relatives and friends to assist in caring for their healthy children.

Healthy siblings must adapt to family changes, including additional responsibilities, a decreased physical and emotional availability from their parents, and emotions such as fear, anger, anxiety, isolation, jealousy, shame, and guilt.^{9,10} Siblings have reported a need for emotional support, because they feel forgotten and strongly affected by their family's life now being focused on the ill brother or sister.¹¹ Healthy siblings need to be comforted, loved, respected, understood, and also cared for during their sibling's illness. One study reported that healthy siblings have relatively lower quality of life during the first 2 months after the diagnosis of cancer for a brother or sister than peers.¹² The effect to siblings can continue throughout the illness, because school-aged siblings (ages 7-11 years old) have significantly impaired overall quality of life at 2 years after the diagnosis of cancer for a sibling, and some adolescents experience clinically relevant internalizing problems.¹⁰

Almost immediately after a child's condition is diagnosed as cancer, families begin striving to survive.⁸ This includes striving for the ill child to survive, as well as survival of the entire family unit. Family members try to feel hope and have

a positive focus to reduce their feelings of fear and powerlessness. With a belief in a higher spiritual power, family, friends, and staff may still hope for survival of the ill child. Siblings receive hope from peers and teachers at school that their brother or sister will get better. New routines help family members regain control, such as patients going to hospital or regular school, or siblings visiting the ill sibling at the hospital. Some siblings have reported conflicts of loyalty by the need to maintain previous responsibilities (eg, school) and the opportunity to spend time with their ill siblings.⁹ Parents, siblings, and patients strive to stay close to persons who make them feel secure and safe to decrease their loneliness.⁸ Family members have reported that feeling close to the staff make them feel safe and secure, whereas healthy and ill siblings felt it was important to stay close to peers and teachers at school. Healthy siblings have also expressed that they and their ill siblings depend on each other.⁹

Thompson and colleagues (personal communication, July 2010) interviewed bereaved parents and siblings who had experienced the death of a child from cancer. These family members advised other families to have no regrets by doing, or not doing, whatever is needed for their ill child. Not having regrets included spending time and cherishing each moment with their child. Bereaved parents also advised families to avoid second guessing themselves and the decisions they made during the time of treatment. Nurses are in an ideal position to help guide families to do what is needed for the child with cancer, encourage family members to spend time together, and reassure families in their decisions (see Table 2 for examples of family nursing care strategies).

Cultural Considerations

Family considerations in PPC also involve an understanding and appreciation for how culture affects children with cancer and their families' thoughts, feelings, hopes, fears, and illness experience. Nurses must explore and honor cultural beliefs and values to enhance the quality of life for each child and family across the continuum of care. In areas that serve diverse ethnic and spiritual cultures, knowledge and understanding of the basic tenets of those cultures are necessary, but it cannot be assumed that each family or person embraces or practices these tenets in the same

TABLE 1.
Examples of Care Delivery Models for Pediatric Palliative Care

Model	Description	Advantages	Disadvantages
PPC Consultative Service	<ul style="list-style-type: none"> • PPC team provides consultative services, but primary care team retains responsibility for day-to-day patient management • Consult service sees patients throughout the institution with no dedicated unit • Various combinations of inpatient and outpatient services 	<ul style="list-style-type: none"> • Primary treatment team maintains relationship with patient and family to continue continuity of care • Patient and family remain on familiar unit with consistent caregivers, including nursing • Decreases patient or family feelings of abandonment from primary health care team • PPC team can follow patients as they move between units (eg, emergency department to pediatric intensive care to inpatient unit to outpatient clinic setting) 	<ul style="list-style-type: none"> • Primary treatment team may not feel comfortable with transition to PPC goals and thus may not request consult • May not have 24/7 coverage palliative care team • PPC team may feel isolated with no dedicated home unit identity • Staff education on multiple units required for PPC competency • Repetitive educational initiatives mandatory to clarify distinctions between palliative, end-of-life care, and hospice care to promote multidisciplinary acceptance • Minimal dedicated PPC nursing staff on each unit • May be limited to inpatients with no or limited outpatient PPC services • Communication challenges of PPC patient subsequent admissions or discharges or outpatient clinic visits to maintain continuity of PPC
Dedicated PPC Service	<ul style="list-style-type: none"> • PPC is a subspecialty care provider within the institution just as any other service (eg, critical care, general medicine, neurology, hematology or oncology) • PPC is an admitting service • May or may not have dedicated PPC unit versus swing beds throughout the institution 	<ul style="list-style-type: none"> • Nurses and other health care staff with specialty training in PPC • 24/7 availability of PPC staff mandated • Dedicated bereavement staff 	<ul style="list-style-type: none"> • Potential for stigma of “End-of-Life Care” unit • High potential for staff burnout without appropriate support • May have sense of loss of continuity or feelings of abandonment from primary care team • Challenges of continuing services at home if discharge possible and desired and institution does not have home PPC and hospice program
Integrated PPC Initiatives	<ul style="list-style-type: none"> • Institutional PPC team dedicated to establishing PPC as institutional core value • Specialty education and training provided to key members of each unit with oversight by institutional PPC team • Institutional PPC team responsible for developing standards, policies and procedures but not usually direct patient care, although they may be called on as resources for difficult situations 	<ul style="list-style-type: none"> • Institutional PPC team mentors unit-based PPC teams • PPC precepts may be integrated as a core value for all patient care delivery in a given unit and throughout institution • May require less dedicated PPC staff • Maintains continuity with primary care team • Provides support to primary care team to introduce concepts of PPC resources early in the trajectory of illness • May help to transition PPC into institution when funding or staff is limited 	<ul style="list-style-type: none"> • May contribute to silos of PPC with differing standards of care despite oversight of institutional PPC team • Challenges of continuing services at home if discharge possible and desired and institution does not have home PPC and hospice program

TABLE 1.
(Continued)

Model	Description	Advantages	Disadvantages
Integrated Home and Hospital PPC Program	<ul style="list-style-type: none"> • Institutional commitment to comprehensive PPC services in inpatient, outpatient, and home settings • Staff rotations in all settings or separate staff for inpatient, outpatient, and home PPC 	<ul style="list-style-type: none"> • Ideal continuity of care in all patient care settings to promote communication and facilitate seamless care delivery • Ability to provide care in the setting of choice for patient and family at any given time • Consistent PPC contact facilitates communication between providers in all settings • Ability for acute, subacute or respite or home PPC 	<ul style="list-style-type: none"> • Significant financial and staffing commitments from institution • Communication challenges among care delivery settings
Home Hospice and PPC Program	<ul style="list-style-type: none"> • Usually a separate team, within institution or community, to provide home PPC 	<ul style="list-style-type: none"> • Facilitates community involvement of hospice organizations • Patient and family able to be at home rather than hospitalized • Home bereavement support services provided and includes siblings • Facilitates obtaining medications and durable medical equipment home delivery 	<ul style="list-style-type: none"> • Possible feelings of abandonment from primary care team • Communication challenges between primary team and home hospice • Difficult for family to know who to call for questions or care needs • Care limitations based on insurance providers (eg, may have to discontinue palliative chemotherapy) • Usually unable to have skilled nursing care on a regular basis, eg, round the clock or specified number of hours/day; thus burden of day-to-day care usually falls on parents or family at home
Home Care	<ul style="list-style-type: none"> • Typically used when home PPC services unavailable because of limited programs in community or insurance restrictions • Home care RN provides basic skilled nursing needs with oversight of PPC by primary care team 	<ul style="list-style-type: none"> • Patient and family can remain at home with intermittent outpatient clinic visits to primary care team • Home care guided by primary care team or PPC team through frequent communication with home care RN • Can continue palliative treatments not be covered under traditional hospice benefits (eg, palliative chemotherapy, nutritional support) 	<ul style="list-style-type: none"> • Lack of PPC specialty training of home care RNs • Home care RN may not feel comfortable with goals of PPC

TABLE 2.
Nursing Care Strategies for Care of Family Members

Goal	Nursing Care Strategy
Help families regain control	<ul style="list-style-type: none"> • Encourage ill child to attend school (at hospital or regular school) as clinically possible. Even attending for a short time or sporadic attendance may facilitate social networking and increase sense of continuing the “work of childhood.” • Encourage healthy sibling to visit ill child at hospital. • Encourage parent to consider taking sick leave or family leave from work, if possible.
Promote family members to feel safe and secure	<ul style="list-style-type: none"> • Encourage parents to maintain discipline for ill and healthy children. • Establish trusting relationships with parents. • Encourage siblings to remain close to peers, teachers, and ill child. • Encourage parents to spend time with healthy children. • Encourage parents to spend time alone with each other. • Provide honest answers to ill and healthy children’s questions.
No regrets from family members	<ul style="list-style-type: none"> • Help guide parents in decision-making process by providing adequate resources. • Reassure families in their decisions (eg, whatever decision is made, it is the right one for them). • Encourage families to spend and cherish time together.
Decrease sibling loneliness and isolation	<ul style="list-style-type: none"> • Include healthy siblings in conversation. • Provide opportunities for siblings to express their thoughts and concerns and encourage them. • Help inform healthy sibling of the ill child’s status and changing goals of care. • Offer suggestions to involve healthy sibling in care of ill child (eg, make a special gift, read a story, help make a meal, help pick out clothes).

way. As relationships develop with each family, nurses must ask and listen to what this child’s illness means to them and determine how best to meet their needs in a culturally and spiritually sensitive manner. With this knowledge, nurses gain a deeper awareness of the child and family’s strengths and needs for support, and their plan of care can be guided by the child’s and family’s reality.

Spirituality

In addition to cultural considerations, spiritual care is a key component to serving children living with cancer and their loved ones. Spirituality is defined as how persons seek and express meaning and purpose and involves their connectedness to the moment, to self, to others, and to the sacred.¹³ The ability to be in a relationship of “sacred trust” with children and their families in PPC is the foundation of competent clinical practice and meaningful spiritual care.¹⁴ Spiritual care infuses all dimensions of PPC because all treatment decisions and care planning revolve around the meaning of life for this child and family. Spiritual care includes the creation of environments in which children and their families can continue

to grow,¹⁵ especially throughout the illness experience. Attending to a person’s spirit respects the inherent inseparable relationship of mind-body-spirit and honors and responds to the core-being of each person, recognizing his or her uniqueness. The family’s hopes and needs, as they define and prioritize them, will make life most meaningful for them.¹⁶

Each moment of care has a spiritual component and is a potential opportunity to provide compassion and affirmation within the context of a healing environment. Nurses frequently form intimate relationships with pediatric oncology patients and their families and are therefore empowered and uniquely positioned to assume a pivotal role in the delivery of spiritual care. These close relationships are at times challenging because nurses struggle to maintain professional boundaries, while providing adequate and personal support to patients and families. Nurses demonstrate spiritual care by purposeful, active presence, supporting the ill child and family’s established coping strategies, affirming hope through kindness, and gently accompanying the child and family in this often uncertain and painful journey. Nurses are compelled to respond to the suffering induced by pediatric cancer and its treatments and to support

the child and family in their search for meaning and hope within the changing goals of care.¹⁷

Although religious rituals and practices are easily assessed, precise objective assessment of spirituality is difficult. "As soon as one tries to impose an assessment method rigorous enough to maintain reliability, validity may suffer as the essence of another's spirituality may be lost."^{18(p. 735)} Assessing spirituality and spiritual needs is intuitive, interpersonal, and altruistic¹⁹ and requires discerning and interpreting perception and experience.²⁰ Spiritual assessment involves asking and listening to what is important to the patient.²¹ In pediatric populations, expression of spirituality is related to developmental age and often centers on the child's understanding of life, as he or she experiences it day-to-day. The best spiritual assessments are ongoing and allow children to tell their life stories, over time, as trusting relationships with caregivers are developed.²² Spiritual concerns of ill children may include love, the meaning of their illness, safety, forgiveness, loneliness, separation from family and friends, hope, how they will be remembered, and how their lives have made a difference in the world.²³

Communication

Communication is the basis of a human connection and, as such, is the basis for a relationship that allows nurses and other clinicians to learn from the ill child with cancer and the child's family what they most value and are most concerned about. Communication involves listening, sharing, and soliciting information and conveying empathy.²⁴ Outcomes of a clinical relationship involving trusted communication between the ill child, the child's family, and the oncology nurse or other clinicians include effective and collaborative treatment decision making that includes the ill child as developmentally and clinically possible and diminishes the likelihood of confusion about the illness and its treatment.²⁵⁻²⁸ Incomplete, insensitive, or confusing communication is distressing to the ill child and his or her family.²⁹ Because of the positive and negative outcomes that can result from communication in PPC, nurses and other clinicians are expected to effectively communicate with ill children of diverse ages, cultures, and clinical situations.³⁰⁻³²

Communication in PPC always occurs within the context of the child's family. Families have

established styles for communicating, and the clinicians interacting with the family will be most effective if they have carefully assessed the family's preferred style of communicating, especially about illness.³³⁻³⁵ Parents are likely to have preferences about who, when, and how illness-related information is shared with their ill child and the child's siblings. Clinicians need to directly ask parents about their preferences for sharing illness information. If parents indicate a preference to do this themselves, clinicians may benefit the planned parent effort by providing examples of ways to share such information. In this way, the parents may be better prepared for this role and thus more likely to share information with their ill child and well children.

Multiple guides are available for clinicians to use in PPC communication.³⁶⁻³⁸ These guides all have in common the recognition of the importance of the human connection between care provider and child and family, the need to carefully prepare for sharing and eliciting information, and feelings and the certainty that communication of this nature is never a one-time event but instead may need to be ongoing.³⁹ In addition, these guidelines do not rely on a single way of communicating but instead combine verbal and nonverbal modes. Example guides include the SPIKES format, the Six E's of Communication (Table 3), or the 7-Step Communication tool.

Communication efforts, despite careful planning, do not consistently go well and may not yield the positive outcomes noted. It is essential that clinicians verify understanding of the information that was communicated. This requires skill so as not to overwhelm the ill child and family or to imply that they need to hear it again. The use of a multidisciplinary team with members skilled at

TABLE 3.
Example Communication Guide: Six Es of Communication

Six Es of Communication

1. Establish an agreement about communication.
2. Engage child at opportune time.
3. Explore what child already knows.
4. Explain medical information according to child's developmental status and needs.
5. Empathize with child's emotions.
6. Encourage child that you will be there when needed.

Data from Beale et al.³⁷

psychosocial communication is paramount. Often the nurse is in a unique role to clarify how family members interpreted information shared with them and to then inform the primary oncology team of any perceived misunderstandings. It is possible that the clinician will either make statements that were not what he or she wanted to say or meant to say. In either case, both the clinician and the ill child or family can be disappointed by the communication attempt. In such cases, ill children and family members have been remarkably receptive to a clinician who returns after a disappointing communication effort to apologize and ask for a second opportunity to communicate in a way that the clinician meant or now prefers.

Ethical Standards

With communication serving as the foundation of human connection, bioethical principles in PPC significantly contribute to the relationship between clinicians, patients, and their family members.⁴⁰ These principles include beneficence, nonmaleficence, and autonomy. Beneficence supports the duty to promote the well-being of child patients, provide emotional support to families, and honor their rights to shared decision making and to participate as integral members of the health care team. Non-maleficence requires that treatment decisions consider the likelihood of causing more harm than benefit. Autonomy respects the dignity of children and families, their right to the knowledge needed to make informed decisions, and the minor's right to assent to treatment decisions.⁴⁰ Nurses caring for children with life-threatening illness and their families are bound by these principles in their role as primary advocates for the patient.¹⁷ Nurses must assertively advocate for ongoing, effective symptom management to allow patients' participation in the highest quality of life possible, however ill children and their families define it.⁴

In addition to the ethical standards for patient advocacy, the nursing role includes high ethical standards for creating and maintaining ethical environments. The Code of Ethics for Nurses⁴¹ mandates that nurses respect the dignity and uniqueness of the person and consider lifestyle, values, and spiritual beliefs in planning patients' care. As PPC providers who meet and enter into the lives of the children with cancer and their

families, nurses are faced with the moral challenge to address both the vulnerability and suffering of patients and families, colleagues, and themselves.^{14,42} Nurses have an ethical responsibility in every dimension of practice, and creating a climate of moral respect is essential to therapeutic effectiveness.⁴³ Nurses are pivotal in integrating pediatric palliative services into the plan of care for children with cancer and their families. Nurses encourage participation and choices in the plan of care on the basis of children's ability and developmental level. Care is thus personalized to the unique person with the disease.^{4,44} Doing so places treatment of the disease within the context of a person's mind, body, and spirit and facilitates healing, regardless of the outcome of attempts to cure.⁴⁴

Furthermore, nurses' primary commitment to the patient and intraprofessional collaboration are essential to addressing and meeting the complicated needs of pediatric oncology patients.⁴¹ Shared clinical decision making must respect the values and goals of patients, families, and the knowledge and experience of clinicians (C. Taylor, personal communication, May 2008). Nurses are in a unique position to provide accurate and complete information to families, inform interdisciplinary health care team members of the wishes of the ill child and the family, ensure that clinical decisions reflect the values and goals of the child and his or her family, and support all members of the health care team. Throughout the journey, the nurse must be central to assuring that difficult conversations remain compassionately child-focused and that decisions reflect family values and the best interests of the child.⁴⁵ As moral agents, nurses bear witness to the process of this most difficult journey, regardless of its end.

PEDIATRIC PALLIATIVE CARE AT THE END OF LIFE

Symptoms

When the medical decision has been made that no curative options remain for a child, certain decision-making discussions (eg, allow natural death, do not resuscitate, phase I study, terminal care, withdrawal of support) are probably to occur, and palliative and end-of-life care become the focus.⁴⁶ Many children with advanced cancers

have one or more distressing symptoms that require adequate and effective assessment to guide selection of appropriate interventions. Attempts to alleviate pain and distressing symptoms of dying children with cancer are often unsuccessful.⁴⁷ Palliative care should be offered to children and adolescents with high-risk cancers and certainly in the setting of relapsed or refractory disease, including those on phase I protocols.⁴⁸ Few studies to date have addressed symptoms or the quality of life experienced by children with or dying of cancer.⁴⁹

Little evidence exists related to symptom distress for children with cancer at end of life, but pain and its medical management are commonly addressed.⁵⁰⁻⁵⁷ A wide variety of symptoms are reported in pediatric patients with advanced cancer. The most common symptoms include pain, fatigue, dyspnea, nausea or vomiting, anxiety, and weight loss or cachexia.⁵⁸⁻⁶² Parents have reported that their child was “suffering,” and, in many cases, interventions were not adequate to relieve symptom distress.⁴⁷ The perceived suffering of a child affects the entire family, and health-related quality of life is dramatically influenced by symptom distress.⁶²⁻⁶⁴ However, symptoms that may be of most concern to clinicians may not be the symptoms of most concern to the parents; thus, part of the strategy of nursing care is to have parents identify the symptom/s that is/are of most concern to them so that priority attention can be given to those. Thus, parents may be comforted and supported in their efforts to be a good parent.

Wolfe et al⁴⁷ found that bereaved parents perceived their dying children most frequently experienced symptoms of pain, fatigue, or dyspnea. Sadly, parents perceived that only 27% of children with pain and 16% with dyspnea received symptom relief. Attempts to alleviate symptoms in dying children were often unsuccessful; thus, these children experienced substantial suffering at the very end of life. In a follow-up study, Wolfe et al⁶⁴ again reported that the most frequent symptoms experienced by children with cancer at end of life included fatigue, pain, dyspnea, and anxiety, but the degree of suffering had diminished with the integration of PPC services compared with the first cohort in the 2000 study⁴⁷ when these services were not available. The degree of perceived suffering shows the potential effect of quality of life, functional status, and symptom distress on the long-term bereavement and func-

tion of family survivors. In addition to fatigue, pain, dyspnea, and anxiety, children with advanced cancers may have specific symptoms related to the type and location of their malignancy (examples in Table 4).

Hopefulness

Adolescents with newly diagnosed cancer and at key points during the first 6 months of treatment identified the importance of remaining hopeful for a return to health, a normal life, and planning for a future. Nursing roles that positively assisted them in achieving their hopes included humor, overt caring, and support of adolescents' self-care behaviors.^{65,66} Adolescents at end of life identified the importance of hopefulness in terms of not suffering when dying and for the comfort of their survivors, particularly their family members and their health care providers.⁶⁷ Important for clinicians is to know that adolescents tend to comprehend their illness status, and, although they may prefer not to speak of this status, their hopes change from cure and a normal life to hopes that match their now more serious clinical status. Knowing that cure is not the only hope of seriously ill adolescents may facilitate the efforts of nurses and other clinicians to discuss with the adolescents their hoped-for objects. Children, adolescents, and parents report recognizing that some clinicians are not comfortable discussing hopes with them when the illness has progressed and will instead repeat the facts related to the progressed illness state. A well-tested clinical prompt to facilitate a discussion about hopefulness and the hoped-for object is, “please share with me what you are hoping for now.” Parents have similarly indicated that hopefulness and the encouragement or at least support of their hope by their child's clinicians from diagnosis forward sustains them in their efforts to continue to provide care and protection for their ill child.^{68,69}

Good Parent

Parents of children and adolescents with incurable cancer are probably involved in end-of-life care decision making on behalf of their ill child. They describe this decision making as a particularly difficult experience for them.⁷⁰ Parents have identified and labeled a factor that they indicate is central to their end-of-life treatment

TABLE 4.
Examples of Common Symptoms Experienced by Children with Specific Cancers at End of Life^{17,47,50,55-58,60,64}

Malignancy	Symptom	Pathology	Nursing Interventions
Leukemia/ lymphomas	Pancytopenia	Infiltration of bone marrow by leukemic infiltrates	<ol style="list-style-type: none"> 1. Blood product transfusions for comfort 2. Use of dark towels to minimize trauma of visual effect of blood loss 3. Oxygen for comfort if dyspnea noted 4. Techniques to conserve energy (eg, bundling of care) 5. Stool softeners to prevent constipation with rectal bleeding 6. Avoid rectal temperatures and medications 7. Avoid NSAIDs 8. Good mouth care (eg, soft bristle brushes, avoid dental floss) 9. Ice and pressure to affected area
	Dyspnea	Mediastinal mass; anemia	<ol style="list-style-type: none"> 1. Elevate HOB 30°; upright position for sitting or lying 2. Fan blowing gently into face 3. PRBC transfusion if anemia related 4. Opioids as prescribed, titrate to effect 5. Relaxation or distraction techniques 6. Nebulizer treatments as indicated
CNS tumors	Headaches	Increased ICP	<ol style="list-style-type: none"> 1. Pain management paramount 2. Steroids 3. Elevate HOB 30°
	Vomiting	Increased ICP	<ol style="list-style-type: none"> 1. Antiemetics 2. Dietary modifications
	Decreased level of consciousness	Infiltration of tumor	<ol style="list-style-type: none"> 1. Daily schedules posted to help with orientation 2. Consistent caregivers 3. Sensory stimulation (eg, therapeutic touch, music, books on tape)
	Increased oral secretions	Dysphagia; infiltration of cranial nerves by tumor	<ol style="list-style-type: none"> 1. Yankar oral suctioning 2. Side lying position 3. Normal saline nebulizer or humidified air to loosen secretions 4. Adequate tissue or basin for expectoration 5. Limit IV and oral fluids
Bone tumors	Bone pain; destruction of bone	Infiltration of bone by tumor	<ol style="list-style-type: none"> 1. Heat/cold therapies 2. Assisting with palliative radiation therapies
	Decreased mobility	Pain; prosthesis	<ol style="list-style-type: none"> 1. Pain management paramount 2. Modify diet to promote bone health (calcium + vitamin D) 3. Assisted ambulation (eg, wheelchair, walker) 4. Physical and occupational therapy to promote independence
Other solid tumors	Ascites	Tumor cell deposits on visceral or parietal peritoneum, causing mechanical obstruction to lymphatic drainage; most common ascites because of abdominal cancers	<ol style="list-style-type: none"> 1. Management of drains or diuresis 2. Management of dyspnea 3. Assist with abdominal paracentesis 4. Thorough skin assessment and referral to wound care team as appropriate 5. Pain management paramount

TABLE 4.
(Continued)

Malignancy	Symptom	Pathology	Nursing Interventions
Any malignancy	Fever	Infection Tumor: release of pyrogens (TNF- α , IL-6) from tumor or from tumor reactive hypersensitivity reactions; Chemotherapy: fibroblasts, endothelial cells, and macrophages release endogenous pyrogens (IL-1, IL-6, TNF); Radiation: damaged immunocytes and endothelial cells release endogenous pyrogens; Blood products; medications; dehydration	1. Avoid shivering 2. Cool cloths to forehead and axillae 3. Loose-fitting clothing 4. Light cover 5. Oral fluids or ice chips 6. Avoid temperature extremes 7. Fan to keep air circulating 8. Anticipate acetaminophen administration and avoid NSAIDs 9. Fever/neutropenia work-up, depending on recent therapies and clinical status
	Body image changes	Cushingoid appearance from steroids; visible affects of tumor growth, eg, amputation, visible mass, central venous catheters, etc; anorexia/cachexia	1. Psychosocial support with referral to social work or psychology as appropriate. 2. Positioning to avoid constant visualization of affected area 3. Art or music therapies or both 4. Relaxation and distraction techniques 5. Peer support groups from others with similar situations, eg, other children who have adjusted well to amputation, CVLs, etc 6. Dietary counseling, eg, avoid excess salt while on steroids, small frequent meals rather than three normal meals per day; consider referral to nutrition/registered dietician

Abbreviations: NSAIDs, nonsteroidal anti-inflammatory drugs; HOB, head of bed; PRBC, packed red blood cells; CNS, central nervous system; ICP, intracranial pressure; IV, intravenous; TNF- α , tumor necrosis factor α ; IL-6, interleukin-6; IL-1, interleukin-1; CVL, central venous line.

decision making: “trying to be a good parent” to their seriously ill child. On the basis of parents’ responses to open-ended interview questions (please share with me your definition of being a good parent to your child now) about this factor, the following definition of “being a good parent” to a seriously ill child was developed: the good parent makes informed, unselfish decisions in the child’s best interest; provides the basics of food, shelter, and clothing; remains at the child’s side regardless of the circumstances; shows the child that he or she is cherished; tries to prevent suffering and to protect health; teaches the child to make good choices, to respect and have sympathy for others; to know God; advocates for the child with staff; and promotes the

child’s health.⁴⁹ These parents were also able to identify behaviors by clinicians that helped parents achieve their internal definition of being a good parent to their seriously ill child. When describing their definition of being a good parent, parents who made the decision to enroll their child in a phase I clinical trial after being informed that their child’s cancer was incurable were more likely to cite feeling compelled to continue with disease-directed therapy (71% vs 7%), whereas those parents who decided in favor of a do not resuscitate or terminal care option were more likely to cite quality of life (74% vs 3%).⁷¹ These differences suggest that a clinician may be aided in understanding parents’ end-of-life decision making by the aspects of the earlier

definition given emphasis by the parent. Not yet known is if parents' definition of being a good parent differs by their child's treatment context (diagnosis, maintenance, cure, end of life), or if the extent to which parents are able to achieve their internal definition of being a good parent is subsequently associated with their well-being during bereavement. Having a conversation with parents about their definition of being a good parent to their seriously ill child may help clinicians to identify strategies to assist parents in this important effort and may also assist parents in recognizing the aspects of the definition that they have indeed achieved.

Legacy Making

One PPC intervention that can coexist with hopefulness and being a good parent is legacy making. As a possible strategy to decrease suffering of children living with cancer and their family members, legacy making is defined as doing or saying something to be remembered (eg, creating a memory book, giving a special gift).⁷² According to bereaved parent and sibling reports, legacy making can be intentional or serendipitous. Family members reported that some ill children living with advanced cancer did things to be remembered, including making crafts for others, willing away personal belongings, writing letters to loved ones, and giving special gifts. Few ill children explicitly said their intent was to be remembered, yet their actions implied that this was their wish. Legacy making resulted in inspiration for both the children with cancer and their family members. For children whose deaths can be anticipated, efforts to create memories and confirm they are loved and will be remembered are important.⁷³ In the terminal phase of an illness, children of all ages may wish to attend to unfinished business, such as taking a special trip or talking with significant people.⁷⁴ Nurses and other clinicians can help facilitate discussions with ill children and their families about their possible hopes and desires to participate in legacy-making activities. School-age children may be ideal to begin discussions with related to legacy making as children ages 7 to 12 years old begin to understand that death is permanent and universal during Piaget's concrete operational stage of development. This age group coincides with bereaved family members who perceived that

children averaging 12 years of age (SD = 5.27) at the time of death were aware of their impending death and exemplified their death awareness explicitly or through their actions and implied words.⁷² It is also important to remember that some children and their families may still be seeking disease-directed therapy. Legacy making is a palliative care intervention that can also coexist with curative care, and nurses can help individually tailor activities that are sensitive to the goals of children with cancer and their families. Nurses can also encourage awareness of ill children's intentional or serendipitous legacies for families who unfortunately experience the death of their child.

BEREAVEMENT

The death of a child is one of the most stressful events possible, and grieving is a lifelong process.⁷⁵ Grief is a normal, dynamic, individualized process that encompasses physical, emotional, social, and spiritual aspects of persons who lose someone significant, with possible positive and negative consequences.⁷⁶ Grief may lead to great distress as well as personal growth. Parents typically never get over a child's death, but parents in uncomplicated grief learn to adjust and integrate the loss into their lives.⁷⁵ Generally, uncomplicated grief results in eventual signs of healing, such as resuming everyday function, deriving pleasure from life, and establishing new relationships. These persons may experience new capabilities and personal growth after an initial grieving period.

Grief results from the experience of loss, and there are many losses when faced with a life-limiting illness, affecting both patients and their families.⁷⁷ Although grief severity and duration varies for bereaved families, most show similar patterns of grief distress. Heightened symptoms of grief distress characterize complicated grief, a high risk for parents and siblings who experience the death of a child.⁷⁵ Complicated grief deviates from the expected reaction for a given society or culture. This form of grief includes absent grief, delayed grief, and prolonged or unresolved grief. Absent grief includes the inhibition of typical grief expressions or denial of the death and the associated feelings. Delayed grief occurs when a considerable amount of time occurs between the death and

TABLE 5.
Resources for Pediatric Palliative Care

Resources	Available
Web sites	
American Academy of Hospice and Palliative Medicine	www.aahpm.org
American Cancer Society	www.cancer.org
Center to Advance Palliative Care	www.capc.org
Children's Oncology Group	www.childrensoncologygroup.org
Children's Project on Palliative/Hospice Services (ChiPPS)	www.nhpco.org
College of Palliative Care	www.aahpm.org/about/college.html
The Children's Room	www.childrensroom.org
Hospice and Palliative Nurses Association	www.hpna.org
End of Life Nursing Education Curriculum	www.aacn.nche.edu/ELNEC
National Cancer Institute	www.cancer.gov
National Institute of Nursing Research	www.ninr.nih.org
Oncology Nursing Society	www.ons.org
Books	
<i>Standards of Practice for Pediatric Palliative Care and Hospice</i>	NHPCO ⁸⁸
<i>Palliative Care for Infants, Children, and Adolescents</i>	Carter & Levetown ¹⁷
<i>The Fall of Freddie the Leaf: A Story of Life for All Ages</i>	Buscaglia ⁸⁹
<i>The Nature of Suffering and the Goals of Nursing</i>	Ferrell & Coyle ⁹⁰
<i>Continuing Bonds: New Understandings of Grief</i>	Klass, Silverman, & Nickman ⁸²

the onset of grief reactions, from weeks to years. Prolonged grief is associated with persistent depression, loss preoccupation, yearning for the deceased child, and social inhibition that does not transform over time.

Emotional needs of families do not end after a child's death from cancer. Continued contact between bereaved families and health care staff, especially nurses, can be helpful to parents and siblings. Families whose child died 6 to 18 months earlier have expressed that contact initiated by staff members of the intensive care unit staff 1 month after death was valued.⁷⁸ Similarly, Tordes⁷⁹ found that bereaved parents appreciate maintained contact from clinicians by a periodic phone call. Sending cards or notes on holidays, the child's birthday, or the anniversary of the child's death has also been noted as helpful to families.⁸⁰ Although some parents have positive experiences of follow-up visits after their child's death, others become frustrated and feel this contact makes them re-live negative experiences.⁸¹ Although some family members find it helpful and appreciate continued contact with the nurses and other clinicians after the death of their child, it is important to remember that continued contact is not universally helpful to all families.

CONTINUING BONDS

Continued contact between bereaved family members and the deceased child can also be helpful to some parents and siblings. Continuing bonds, or maintaining connections with deceased loved ones, can provide comfort, ease the transition from the past to the future, and facilitate coping for bereaved persons.⁸² A growing body of literature has described various expressions of continuing bonds and suggested that maintaining connections with deceased loved ones is an integral component of adaptation to bereavement.⁸³⁻⁸⁵ Recent work with bereaved parents and siblings who experienced the death of a child from cancer reported on the purposeful (eg, keeping photographs, visiting special locations the child occupied while alive) and nonpurposeful (eg, dreams of the deceased child, signs or visits from the deceased child) nature of continuing bonds, as well as both comforting and discomforting effects.⁸⁶ Although bereaved parents and siblings have mostly reported comforting effects from continuing bonds, discomforting effects occurred for a few persons. Nurses and other clinicians can facilitate discussions with ill children and their families related

to continuing bonds. For example, nurses can assist families to initiate continuing bonds by helping them to create meaning from legacy-making activities their ill child may have participated in before his or her death. Nurses can help interested families to create journals, memory books, photos, videos, or artwork as a means of processing the impending death. Foundations or charity events can be suggested as possible ways to remember and celebrate children's lives. Nurses can reassure family members that continuing bonds are not necessary for all persons or universally helpful. They can offer these loved ones a sense of normalcy and reduce possible guilt felt by those who do not choose to voluntarily maintain connections with the deceased.

SUSTAINING ONE'S SELF AS A PEDIATRIC PALLIATIVE CARE NURSE

Nurses and clinicians who care for children living with and dying of cancer and their families participate in the lived experience of illness and share a parallel suffering that must be acknowledged.^{42,87} It is essential to recognize their own understanding of dying and death, its meaning in their own lives, and their own needs to authentically meet the child and family in their experience and provide effective support (C. Taylor, personal communication, September 2009). Taylor suggested that nurses should become a "healing presence" by being present to oneself, creating an atmosphere of calm, and letting go of personal expectations. Healing presence also means caring for self and

colleagues. It is essential that nurses live a balanced life (eg, healthy eating, exercising, time for reflection and fun), as well as maintain appropriate professional boundaries, encourage self-growth among colleagues; uphold a grateful attitude; create a supportive and nurturing culture; share stories; and offer empathy and activities that comfort and renew their spirits. Nurses must share resources (examples in Table 5) and offer support to each other during shifts and especially after a patient's death. On occasion, nurses and other clinicians can come together to reflect, listen to music, or create something (eg, memorial photo tribute to honor patients who have died)⁹¹; participate in memorial services that honor children who have died and their families; plan celebrations to acknowledge colleagues' accomplishments; and affirm each other in the difficult and rewarding work to nourish and sustain nurses who are privileged to journey together with these most special children and their families.

In conclusion, the term and meaning of PPC is now embedded in the daily care that nurses and other clinicians provide to children living with cancer and their families, from the time of diagnosis, until cure or end of life, and thereafter. Nurses and other clinicians have a great opportunity to provide a meaningful service and play a pivotal role to decrease the physical, psychological, social, and spiritual suffering that children with cancer and their families endure. More work is needed to continue advancing the state of science on PPC so that nurses can continue to provide the best care to enhance the lives of these patients with and dying of cancer.

REFERENCES

1. Friebert S. NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization; April 2009.
2. Knapp CA, Thompson LA, Vogel WB, Madden VL, Shenkman EA. Developing a pediatric palliative care program: addressing the lack of baseline expenditure information. *Am J Hosp Palliat Care* 2009;26:40-46.
3. Duncan J, Spengler E, Wolfe J. Providing pediatric palliative care: PACT in action. *MCN Am J Matern Child Nurs* 2007;32:279-287.
4. American Academy of Pediatrics (AAP) Committee on Bioethics. Palliative Care for Children. *Pediatrics* 2000;106:351-357.
5. Field MJ, Behrman RE. When children die: improving palliative and end-of-life care for children and their families. *Institute of Medicine*. Washington, DC: The National Academies Press; 2003.
6. Center to Advance Palliative Care. Palliative Care Tools, Training and Technical Assistance. 2010. Available at: www.capc.org. Accessed May 3, 2010.
7. Levetown M, Dokken D, Heller KS, et al: for The Initiative for Pediatric Palliative Care (IPPC). A Pediatric Palliative Care Institutional Self-Assessment Tool (ISAT). Newton, MA: Educational Development Center, Inc; 2002.
8. Bjork M, Wiebe T, Hallstrom I. Striving to survive: families' lived experiences when a child is diagnosed with cancer. *J Pediatr Oncol Nurs* 2005;22:265-275.
9. Nollbris M, Enskar K, Hellstrom AL. Experience of siblings of children treated for cancer. *Eur J Oncol Nurs* 2007;11:106-112.

10. Houtzager BA, Grootenhuis MA, Caron HN, Last BF. Quality of life and psychological adaptation in siblings of paediatric cancer patients, 2 years after diagnosis. *Psychooncology* 2004;13:499-511.
11. Murray JS. A qualitative exploration of psychosocial support for siblings of children with cancer. *J Pediatr Nurs* 2002;17:327-337.
12. Houtzager BA, Grootenhuis MA, Hoekstra-Weebers JE, Last BF. One month after diagnosis: quality of life, coping and previous functioning in siblings of children with cancer. *Child Care Health Dev* 2005;31:75-87.
13. Puchalski C, Ferrell B, Virani R, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med* 2009;12:885-904.
14. Browning DM, Solomon MZ. Relational learning in pediatric palliative care: transformative education and the culture of medicine. *Child Adolesc Psychiatr Clin North Am* 2006;15:795-815.
15. Desai PP, Ng JB, Bryant SG. Care of children and families in the CICU: a focus on their developmental, psychosocial, and spiritual needs. *Crit Care Nurs Q* 2002;25:88-97.
16. Friebert S, Ballard K. Spirituality in Pediatric Palliative Care: Family Stories of Relationship. Quality of Life for the Children, The Third Annual Pediatric Palliative Care Conference, District of Columbia Pediatric Palliative Care Collaborative. Washington DC, 2009.
17. Carter BS, Levetown M. *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook*. Baltimore, MD: Johns Hopkins University Press; 2004.
18. Walco GA. Religion, spirituality, and the practice of pediatric oncology. *J Pediatr Hematol Oncol* 2007;29:733-735.
19. Sawatzky R, Pesut B. Attributes of spiritual care in nursing practice. *J Holistic Nurs* 2005;23:19-33.
20. Cobb M, Robshaw V. *The Spiritual Challenge of Health Care*. Edinburgh, Scotland: Churchill Livingstone; 1998.
21. Puchalski C, Hall P, Weaver L, Hupe D, Seely JF. Palliative care and end-of-life education - community-based palliative care education: can it improve care of the terminally ill? *Academic Med* 1999;74:S105.
22. Thayer P. Spiritual care of children with life-limiting illness. *ChiPPS Newsletter*, February 2008. Available at: www.nhpco.org/files/public/ChiPPS/ChiPPS_February_2008.pdf. Accessed July 24, 2010.
23. Amery J. *Children's palliative care in Africa*. Oxford, United Kingdom: Oxford University Press; 2009.
24. Mack JW, Hinds PS. Practical aspects of communication. In: *Textbook of interdisciplinary pediatric palliative care*. Wolfe J, Hinds P, Sourkes B, editors. Philadelphia, PA: Elsevier; 2011. pp 179-189.
25. Hinds PS, Drew D, Oakes LL, et al. End-of-life care preferences of pediatric patients with cancer. *J Clin Oncol* 2005;23:9146-9154.
26. Last BF, Van Veldhuizen AM. Information about diagnosis and prognosis related to anxiety and depression in children with cancer aged 8-16 years. *Eur J Cancer* 1996;32A:290-294.
27. Levetown M. American Academy of Pediatrics Committee on Bioethics. Communicating with children and families: from everyday interactions to skill in conveying distressing information. *Pediatrics* 2008;121:e1441-e1460.
28. Wolfe J, Klar N, Grier HE, et al. Understanding of prognosis among parents of children who died of cancer: impact on treatment goals and integration of palliative care. *JAMA* 2000;284:2469-2475.
29. Contro N, Larson J, Scofield S, Sourkes B, Cohen H. Family perspectives on the quality of pediatric palliative care. *Arch Pediatr Adolesc Med* 2002;156:14-19.
30. Fallat ME, Glover J. American Academy of Pediatrics Committee on Bioethics. Professionalism in pediatrics. *Pediatrics* 2007;120:e1123-e1133.
31. Goldie J, Schwartz L, Morrison J. Whose information is it anyway? Informing a 12-year-old patient of her terminal prognosis. *J Med Ethics* 2005;31:427-434.
32. Ranmal R, Priotor M, Scott JT. Interventions for improving communication with children and adolescents about their cancer. *Cochrane Database Syst Rev* 2008;(4):CD002969.
33. Clarke JN, Fletcher P. Communication issues faced by parents who have a child diagnosed with cancer. *J Pediatr Oncol Nurs* 2003;20:175-191.
34. Parsons SK, Saiki-Craighill S, Mayer DK, et al. Telling children and adolescents about their cancer diagnosis: Cross-cultural comparisons between pediatric oncologists in the US and Japan. *Psychooncology* 2007;16:60-68.
35. Young B, Dixon-Woods M, Windridge KC, Heney D. Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents. *BMJ* 2003;326:305.
36. Baile WF, Buckman R, Lenzi R, Globler G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist* 2000;5:302-311.
37. Beale EA, Baile WF, Aaron J. Silence is not golden: communicating with children dying from cancer. *J Clin Oncol* 2005;23:3629-3631.
38. Von Gunten CF, Ferris FD, Emanuel LL. The patient-physician relationship. Ensuring competency in end-of-life care: communication and relational skills. *JAMA* 2000;284:3051-3057.
39. Ishibashi A. The needs of children and adolescents with cancer for information and social support. *Cancer Nurs* 2001;24:61-67.
40. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. New York, NY: Oxford University Press; 2001.
41. American Nurses Association (ANA). Code of ethics for nurses with interpretive statements. 2005. Available at: <http://nursingworld.org/MainMenuCategories/ThePracticeofProfessionalNursing/EthicsStandards/CodeofEthics.aspx>. Accessed July 24, 2010.
42. Browning D. To show our humanness—relational and communicative competence in pediatric palliative care. *Bioethics Forum* 2002;18:23-28.
43. Levine ME. Nursing ethics and the ethnical nurse. *Am J Nurs* 1977;77:845-849.
44. Rushton CH. A framework for integrated pediatric palliative care: being with dying. *J Pediatr Nurs* 2005;20:311-325.
45. Jacobs HH. Ethics in pediatric end-of-life care: a nursing perspective. *J Pediatr Nurs* 2005;20:360-369.
46. Wolfe J, Klar N, Grier HE, et al. Understanding of prognosis among parents of children who died of cancer: impact on treatment goals and integration of palliative care. *JAMA* 2000;284:2469-2475.

47. Wolfe J, Grier HE, Klar N, et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 2000;342:326-333.
48. Johnston DL, Nagel K, Friedman DL, Meza JL, Hurwitz CA, Friebert S. Availability and use of palliative care and end-of-life services for pediatric oncology patients. *J Clin Oncol* 2008;26:4646-4650.
49. Hinds PS, Oakes LL, Hicks J, et al. "Trying to be a good parent" as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children. *J Clin Oncol* 2009;27:5979-5985.
50. Kane JR, Primomo M. Alleviating the suffering of seriously ill children. *Am J Hosp Palliat Care* 2001;18:161-169.
51. Kane JR, Barber RG, Jordan M, Tichenor KT, Camp K. Supportive/palliative care of children suffering from life-threatening and terminal illness. *Am J Hosp Palliat Care* 2000;17:165-172.
52. Frager G. Pediatric palliative care: building the model, bridging the gaps. *J Palliat Care* 1996;12:9-12.
53. Liben S. Pediatric palliative medicine: obstacles to overcome. *J Palliat Care* 1996;12:24-28.
54. Attig T. Beyond pain: the existential suffering of children. *J Palliat Care* 1996;12:20-23.
55. Collins JJ. Intractable pain in children with terminal cancer. *J Palliat Care* 1996;12:29-34.
56. Hunt A, Goldman A, Devine T, Phillips M. Transdermal fentanyl for pain relief in a paediatric palliative care population. *Palliat Med* 2001;15:405-412.
57. Kenny NP, Frager G. Refractory symptoms and terminal sedation of children: Ethical issues and practical management. *J Palliat Care* 1996;12:40-45.
58. Hinds PS, Quargnenti AG, Wentz TJ. Measuring symptom distress in adolescents with cancer. *J Pediatr Oncol Nurs* 1992;9:84-86.
59. Hongo T, Watanabe C, Okada S, et al. Analysis of the circumstances at the end of life in children with cancer: symptoms, suffering and acceptance. *Pediatr Int* 2003;45:60-64.
60. Prichard M, Burghen E, Srivastava DK, et al. Cancer-related symptoms most concerning to parents during the last week and last day of their child's life. *Pediatrics* 2008;121:e1301-e1309.
61. Houlahan KE, Branowicki PA, Mack JW, Dinning C, McCabe M. Can end of life care for the pediatric patient suffering with escalating and intractable symptoms be improved? *J Pediatr Oncol Nurs* 2006;23:45-51.
62. Woodgate RL, Degner LF, Yanofsky R. A different perspective to approaching cancer symptoms in children. *J Pain Symptom Manage* 2003;26:800-817.
63. Roddenberry A, Renk K. Quality of life in pediatric cancer patients: The relationships among parents' characteristics, children's characteristics, and informant concordance. *J Child Fam Studies* 2008;17:402-426.
64. Wolfe J, Hammel JF, Edwards KE, et al. Easing of suffering in children with cancer at the end of life: Is care changing? *J Clin Oncol* 2008;26:1717-1723.
65. Hinds P, Martin J. Hopefulness and the self-sustaining process in adolescents with cancer. *Nurs Res* 1988;37:336-340.
66. Hinds P, Quargnenti A, Bush A, et al. An evaluation of the impact of a self-care coping intervention on psychological and clinical outcomes in adolescents with newly diagnosed cancer. *Eur J Oncol Nurs* 2000;4:6-17.
67. Hinds PS. The hopes and wishes of adolescents with cancer and the nursing care that helps. *Oncol Nurs Forum* 2004;31:927-934.
68. Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Hope and prognostic disclosure. *J Clin Oncol* 2007;25:5636-5642.
69. Mack JW, Wolfe J, Grier HE, Cleary PD, Weeks JC. Communication about prognosis between parents and physicians of children with cancer: parent preferences and the impact of prognostic information. *J Clin Oncol* 2006;24:5265-5270.
70. Hinds PS, Oakes L, Furman W, et al. End-of-life decision making by adolescents, parents, and healthcare providers in pediatric oncology: research to evidence-based practice guidelines. *Cancer Nurs* 2001;24:122-134.
71. Maurer SH, Hinds PS, Spunt SL, Furman WL, Kane JR, Baker JN. Decision making by parents of children with incurable cancer who opt for enrollment on a Phase I trial compared with choosing a do not resuscitate/terminal care option. *J Clin Oncol* 2010;28:3292-3298.
72. Foster TL, Gilmer MJ, Davies B, et al. Bereaved parents' and siblings' reports of legacies created by children with cancer. *J Pediatr Oncol Nurs* 2009;26:369-376.
73. Levetown M, Liben S, Audet M. Palliative care in the pediatric intensive care unit. In: Carter BS, Levetown M, eds. *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook*. Baltimore, MD: Johns Hopkins University Press; 2004. pp 273-291.
74. Armstrong-Dailey A, Zarbock SF. *Hospice Care for Children*. New York, NY: Oxford University Press; 2001.
75. Himmelstein BP, Hilden JM, Boldt AM, Weissman D. Pediatric palliative care. *N Engl J Med* 2004;350:1752-1762.
76. Jacob SR. An analysis of the concept of grief. *J Adv Nurs* 1993;18:1787-1794.
77. Lobb EA, Clayton JM, Price MA. Suffering, loss and grief in palliative care. *Aust Fam Physician* 2006;35(10):772-775.
78. Macnab AJ, Northway T, Ryall K, Scott D, Straw G. Death and bereavement in a paediatric intensive care unit: parental perceptions of staff support. *Paediatr Child Health* 2003;8:357-362.
79. Todres ID. Communication between physician, patient, and family in the pediatric intensive care unit. *Crit Care Med* 1993;21(9 Suppl):S383-S386.
80. Brown PS, Sefansky S. Enhancing bereavement care in the pediatric ICU. *Crit Care Nurse* 1995;15:59-64.
81. Midson R, Carter B. Addressing end of life care issues in a tertiary treatment centre: Lessons learned from surveying parents' experiences. *J Child Health Care* 2010;14:52-66.
82. Klass D, Silverman PR, Nickman SL. *Continuing bonds: new understandings of grief*. Washington, DC: Taylor & Francis; 1996.
83. Asai M, Fujimori M, Akizuki N, Inagaki M, Matsui Y, Uchitomi Y. Psychological states and coping strategies after bereavement among the spouses of cancer patients: a qualitative study. *Psychooncology* 2010;19:38-45.
84. Davies R. Mothers' stories of loss: their need to be with their dying child and their child's body after death. *J Child Health Care* 2005;9:288-300.
85. Packman W, Horsley H, Davies B, Kramer R. Sibling bereavement and continuing bonds. *Death Studies* 2006;30:817-841.

86. Foster TL, Gilmer MJ, Davies B, et al. Comparison of continuing bonds reported by parents and siblings after a child's death from cancer. *Death Studies* [In press].

87. Doyle D. *Oxford Textbook of Palliative Medicine*. New York, NY: Oxford University Press; 2005.

88. NHPCO. *Standards of Practice for Pediatric Palliative Care and Hospice*. Alexandria, VA: National Hospice and Palliative Care Organization (NHPCO); 2009.

89. Buscaglia L. *The Fall of Freddie the Leaf: A Story of Life for All Ages*. Thorofare, NJ: SLACK Inc.; 1982.

90. Ferrell B, Coyle N. *The Nature of Suffering and the Goals of Nursing*. New York, NY: Oxford University Press; 2008.

91. Hospice and Palliative Nurses Association. HPNA photo memorial tribute. 2010. Available at: www.hpna.org/DisplayPage.aspx?Title=HPNA%20Photo%20Memorial%20Tribute. Accessed July 24, 2010.
