

REVIEW

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## The Nursing Dimension of Providing Palliative Care to Children and Adolescents with Cancer

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**Abstract:** Palliative care for children and adolescents with cancer includes interventions that focus on the relief of suffering, optimization of function, and improvement of quality of life at any and all stages of disease. This care is most effectively provided by a multidisciplinary team. Nurses perform an integral role on that team by identifying symptoms, providing care coordination, and assuring clear communication. Several basic tenets appear essential to the provision of optimal palliative care. First, palliative care should be administered concurrently with curative therapy beginning at diagnosis and assuming a more significant role at end of life. This treatment approach, recommended by many medical societies, has been associated with numerous benefits including longer survival. Second, realistic, objective goals of care must be developed. A clear understanding of the prognosis by the patient, family, and all members of the medical team is essential to the development of these goals. The pediatric oncology nurse is pivotal in developing these goals and assuring that they are adhered to across all specialties. Third, effective therapies to prevent and relieve the symptoms of suffering must be provided. This can only be accomplished with accurate and repeated assessments. The pediatric oncology nurse is vital in providing these assessments and must possess a working knowledge of the most common symptoms associated with suffering. With a basic understanding of these palliative care principles and competency in the core skills required for this care, the pediatric oncology nurse will optimize quality of life for children and adolescents with cancer.

**Keywords:** palliative care, pediatrics, nursing, cancer

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*Clinical Medicine Insights: Pediatrics* 2012:6 75–88

doi: [10.4137/CMPed.S8208](https://doi.org/10.4137/CMPed.S8208)

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## Introduction

Palliative care for children and adolescents with cancer includes interventions that focus on the relief of suffering, optimization of function, and improvement of quality of life at any and all stages of disease. Goal setting for this care is most effectively accomplished by a team that includes the child, parents, and siblings working in partnership with a multidisciplinary medical team. The multidisciplinary team often includes, but is not limited to, child life experts, social workers, physical therapists, pharmacists, nurses, and physicians from a host of specialty services.

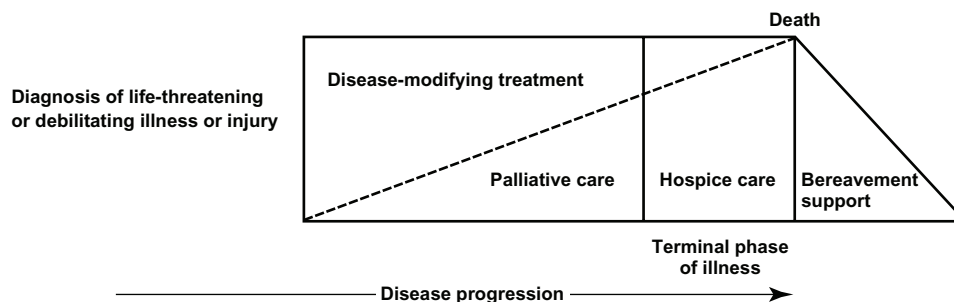
Nurses play a key role on the palliative care team. They often bring cohesion and care coordination to the multidisciplinary effort. Nurses are often the first to identify the suffering needs of a patient.<sup>1</sup> They are present at the bedside or in the clinic for extended periods of time and, thus, have unique opportunities to assess and explore child and family needs. This perspective places them in a vital position to facilitate care directed towards the relief of suffering and the implementation of palliative care. However, according to the End-of-Life Nursing Education Consortium (ELNEC) project, a national end-of-life educational program administered by City of Hope National Medical Center and the American Association of Colleges of Nursing (AACN), fewer than 14,000 nurses have been formally trained in palliative care.<sup>2</sup> Other national and international palliative care training programs are available (eg, the Initiative for Pediatric Palliative Care (IPPC), the Stanford End of Life Curriculum Project, and the Resolve Through Sharing program) that focus on pain and symptom management, communication strategies, care at the end of life, ethics, and other aspects of palliative care; however, access to these programs by nurses remains

a challenge. Thus, the vast majority of nurses are not equipped with the specialized knowledge and skills needed to provide quality palliative care to children and their families.

The role of the physician in providing palliative care to children and adolescents with cancer has been well described in the literature, yet relatively little has been written about the unique role that nurses play on the palliative care team.<sup>3,4</sup> The purpose of this paper is to discuss the nursing dimension of palliative care for children and adolescents with cancer. We will describe the concurrent palliative care model, review the impact of patient prognosis on palliative care, and discuss the establishment of realistic treatment goals. We will also cover the assessment of patient needs as well as the prevention and relief of suffering.

## The Delivery of Palliative Care Concurrently with Life Prolonging Care

More than a decade has passed since the American Academy of Pediatrics (AAP)<sup>5</sup> and the Institute of Medicine (IOM)<sup>6</sup> called for the integration of palliative care into ongoing medical management of children with life-threatening illnesses from the point of diagnosis to the end of life (Fig. 1). Since that time, models of integrated pediatric palliative care have been developed in which both curative therapy and palliative care coexist. As cure-oriented treatment options decrease, the role of palliative care increases. Hospice services are offered at the end of the continuum of care.<sup>7</sup> In this model, concurrent care is defined as the introduction of palliative care principles at the time of a life-threatening diagnosis, with increasing support over time as the disease progresses that includes multidimensional assessment



**Figure 1.** Concurrent/integrative model of palliative care.

A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report. Chapter 1. Framework. National Quality Forum. Washington, DC, 2006, p. 3.



to identify, prevent, and alleviate suffering.<sup>8</sup> These models have been supported by studies with adult patients demonstrating that palliative care does prolong life,<sup>9</sup> is effective in improving quality of care,<sup>10</sup> decreases hospital costs,<sup>9</sup> and decreases caregiver burden.<sup>11,12</sup> In fact, the American Society of Clinical Oncology has recently released a provisional clinical opinion based on available trials advocating the early integration of palliative care into standard cancer treatment for malignancies with high symptom burden.<sup>13</sup> However, many challenges exist in the implementation of these integrated models including the economic limits of the current health care environment, the lack of necessary tools and skills needed by health care providers, and the misalignment of palliative care exclusively to end-of-life care needs. Despite the fact that palliative care is now widely recognized as a critical part of excellent care for children with life-limiting diseases such as cancer, patients continue to receive this care very late in their illness trajectory.<sup>14,15</sup>

Successful delivery of a concurrent model of care to children with cancer depends on establishing a relationship with the child and family that is built on trust. Parent/caregiver uncertainty regarding the changes in medical therapy that may occur once palliative care goals are established may lead to stress, anxiety, and lack of commitment towards these goals.<sup>16</sup> A shared commitment to goals directed towards cure and life-prolongation measures, as well as an equal commitment to symptom management and relief of suffering, are critical to the successful implementation of a concurrent care model.<sup>17</sup> This shared commitment requires that the health care team and nurses in particular, are comfortable with the core competencies regarding psychosocial assessment, symptom management, management of distress, communication, and transition of care. As such, a second important determinant of the successful delivery of a concurrent model of care to children with cancer is that nurses across all levels of the cancer care continuum, from primary care nurses in the community, to inpatient nurses on the oncology wards, and to specifically trained nurses in the intensive care unit, possess the basic core skills as well as a working understanding of the principles of palliative care.<sup>18</sup> While specialists in palliative care services should be available to all patients when their needs become complex, there is a

range of basic goals that needs to be integrated across the care continuum.

## The Importance of Understanding the Patient Prognosis

In order to provide quality palliative care, it is important that the care team, including the parents, develop as clear an understanding of the patient's prognosis as possible. Prognostic uncertainty is a familiar experience in the care of children with life-threatening illnesses including cancer.<sup>19</sup> While much of childhood cancer treatment can be characterized by success with more than 80% of children becoming 5-year survivors of their cancer,<sup>20</sup> cancer remains the leading cause of death by disease among US children 1 to 14 years of age.<sup>21,22</sup> Several high-risk cancer diagnoses remain, and long-term survivors are at an elevated risk of death due to recurrence of the primary disease or as a result of late effects of therapy. Thus, there continues to be a population of children with life-threatening cancer diagnoses that defy prognostic estimations and present challenges. Overly optimistic estimates of prognosis remain a common barrier to the initiation of palliative care.<sup>23,24</sup>

Nurses can provide families with the much needed reassurance that a focus on relief of suffering does not mean that curative or disease-modifying treatments will be abandoned if they remain appropriate. By framing the principles of palliative care in a concurrent care model, unnecessary delays in providing children the treatment they need may be avoided, as ongoing multidimensional assessment and open communication are more likely to result in identification of distressing symptoms. While empirical support for the avoidance of these delays is lacking, researchers have found that concurrent care models have led to higher scores for quality of life and mood in adult patient populations. Unfortunately, palliative care is not always presented or viewed in that manner by the medical providers. In a study investigating the challenges that exist in providing pediatric palliative care to inpatient populations, Docherty et al described providers' hesitation to initiate palliative care discussions and interventions until they were certain that the child was "beginning to die."<sup>25</sup> In light of prognostic uncertainty and the desire to remain hopeful, such a practice may result in much avoidable suffering. This prognostic uncertainty is particularly relevant in



pediatric oncology as many conditions have a highly variable course and the likelihood of treatment success is difficult to establish. However, nurses trained in the principles and core competencies of palliative care with the goals of alleviating distress, assisting in complex decision making, and enhancing overall quality of life, may benefit children and families through their understanding and commitment to concurrent care models.<sup>26</sup> In addition, such training and knowledge will empower the nurse in medical team meetings and other settings to advocate on behalf of children. Such advocacy often takes the form of clarifying realistic goals of care that can guide decision making. The establishment of such realistic, objective goals provides the framework for the delivery of effective palliative care.

### Establishing Realistic Goals of Care

For as long as the practice of medicine has existed, there have been two primary goals of care: (1) to cure disease and (2) to relieve suffering in patients.<sup>27</sup> Within those two broad categories, there are many specific goals unique to each individual patient that will help satisfy the care mission. Palliative care seeks to relieve the physical, emotional, social, and spiritual distress produced by life-limiting conditions; to assist in complex decision making; and to enhance the quality of life.<sup>28,29</sup> To most effectively do so, providers must guide realistic goal setting for the patient. These goals of care should be rooted in the personal beliefs of the patient and family and based on the clinical condition. Clearly, whenever possible, the goals of the child should be solicited and respected.<sup>5,30</sup> Many publications, as well as national guidelines, have reaffirmed the importance of developing goals of care; notably, the Medicare Hospice Benefit has long contained a provision mandating individualized treatment plans including the establishment of goals of care for patients.<sup>31-33</sup> The establishment of goals of care has become an essential component of quality palliative medicine.<sup>4,34</sup> These goals of care should account for the physical, emotional, social, and spiritual distress experienced by patients and their families. Nurses are often best situated to evaluate this distress because of the amount of time they spend with patients and their families compared with other medical team members.

Data suggest that most patient goals can be categorized into general areas pertaining to various aspects

of life.<sup>35,36</sup> This categorization may assist families in establishing more broad-based goals of care. However, for many children, including those with cancer, goals of care often remain poorly delineated because they are not discussed thoroughly and openly.<sup>28</sup> Pediatric nurses rated “uncertainty about the goals of care” as second only to “lack of opportunity to debrief after death,” in a study of obstacles to the provision of palliative care.<sup>37</sup> For palliative care to be successful, there must be candid exchanges between the patient, family, and the health care team. Unfortunately, such conversation often does not occur in a timely manner to impact outcomes and improve quality of life.

To date, little has been published on specific palliative care goals for children with cancer, but there are studies that can provide a foundation for nurses to advocate from on behalf of their patients. For example, it is clear that a restoration or maintenance of health, to some degree, is a common goal among this patient population. In a recent report, the goals of care ascertained during the initial palliative care consultation among 50 consecutive pediatric patients were reviewed. In that analysis, nearly every (49/50) patient and family member verbalized at least one goal pertaining directly to physical health and independence; 25 verbalized a goal that specifically and directly addressed health maintenance or improvement.<sup>34</sup>

Although this study included oncology and non-oncology patients, the findings are quite consistent with those reported by Wolfe et al among a purely pediatric oncology population.<sup>19</sup> In her report, during the parent-defined end-of-life care period, two thirds of parents voiced that the primary goal of cancer-directed therapy was to extend life, while a fourth of the parents voiced that the primary goal was specifically to cure the cancer. In another study of pediatric oncology patients authored by Hinds et al, nearly 60% of parents cited trying to find a cure or prolonging life as factors that influenced their end-of-life decision for their child.<sup>38</sup> Clearly, these studies suggest that quality palliative care for pediatric oncology patients will likely require plans that support the restoration or maintenance of health. Moreover, these findings suggest that concurrent palliative and curative care is consistent with the aspirations of pediatric oncology patients and their families. Present day practice, advocated by the American Academy of Pediatrics





and the Institute of Medicine, suggests that palliative care should be initiated at the time of diagnosis and continue concurrently with curative therapy, taking a more predominant role at the end of life.<sup>5,6,33</sup>

Unfortunately, families and patients often offer goals that are vague and general. In one report, nearly half the children/families who expressed a goal pertaining to the psychological and spiritual realm verbalized a desire to be happy.<sup>34</sup> While ascertaining such general goals may help guide overall care planning, it is imperative that the palliative care practitioner explore these goals more explicitly. The true value of establishing goals appears to be derived from the very unique goals specific to each individual patient. Such goals cannot often be anticipated or predicted but only brought to light through detailed and candid discussion. As such, goals within the different domains of life (eg, psychological, social, and environmental) should be specifically explored and addressed.<sup>34</sup> The bedside and clinic pediatric oncology nurse is perfectly positioned to facilitate such discussion.

In addition to identifying objective, specific goals for each individual patient, there are many other challenges in developing effective goals of care. For example, patient goals are likely to be dynamic and changing based on both the personal life and medical condition of the patient. Nurses should be cognizant of this potential for change and continually reassess as well as reaffirm the patient's/family's goals of care. Arguably, the greatest benefit of the paradigm shift to the current doctrine of concurrent curative therapy and palliative care is that a gradual transition in goals may occur. As disease direction changes and end of life approaches, patients will often have a change in their goals of care. The implementation of concurrent care early in the disease process, with the same nurses providing all forms of care throughout, should facilitate a smoother transition in the goals of care. Consequently, it is important that palliative care be administered early in children diagnosed with cancer. Unfortunately, this appears to be an unusual practice. In one survey of over 300 pediatricians, only 15% of participating physicians would recommend early referral for palliative care for children with cancer.<sup>39</sup> In contrast, 44% would make such a recommendation at the end of life. Pediatric nurses, empowered with the skills and understanding of quality palliative care, can keep the care team focused upon palliative

care goals and help to ensure that these principles are integrated into the care model throughout the entire clinical course, even when formal palliative care consultation is not solicited.<sup>18</sup>

One final obstacle in developing goals of care is to ensure that all members of the health care team understand and work towards achieving the goals delineated by the patient. Although seemingly straightforward, this process is often complicated by poor communication of goals and the imposition of personal beliefs maintained by members of the medical team. Davies et al recently reported that discrepancies in treatment goals between staff members and the patient's family is one of the most common barriers to optimal pediatric end-of-life care.<sup>40</sup> Again, the oncology nursing staff may serve a fundamental role in helping to ensure that clinical care, among all services, is consistent with the goals delineated by the patient and/or family.

The Education for Physicians on End-of-life Care (EPEC) Handbook recommends a 7-step approach for the development of effective goals of care.<sup>27</sup> Clearly, effective communication is pivotal to quality palliative care, and others have advocated similar approaches (Table 1).<sup>41-46</sup>

A recent analysis revealed that barriers to effective communication were one of the primary perceived factors that interfered with optimal end-of-life pediatric care.<sup>40</sup> Data suggest that parents want clinicians to discuss advance care options and to assist them in such complex decision making.<sup>47,48</sup> Although the oncology nurse may not be the one spearheading such discussions, the nursing input may prove instrumental in ensuring that such discussions occur, and that patient preferences are verbalized. In a review of the literature on nursing roles and strategies for end-of-life decision making, information broker, supporter, and advocate emerged as key roles that nurses play in the adult acute care setting.<sup>49</sup> These roles are equally relevant in the pediatric oncology environment. First, as information brokers, pediatric oncology nurses provide information about the child and family to the health care team, provide information to the child and family about treatment plans and goals, and coordinate discussions between the family and health care team. Second, nurses provide an important source of emotional support to the child and family as they attempt to comprehend and assess



**Table 1.** Principles of communication with a seriously ill child and the child's family.

<b>7-step communication tool<sup>41</sup></b>	<b>Guidelines for communication of the diagnosis<sup>42</sup></b>	<b>Six E's of communication<sup>43</sup></b>	<b>SEGUE<sup>44</sup></b>	<b>PACE<sup>45</sup></b>	<b>SPIKES<sup>46</sup></b>
1. Prepare for the discussion	1. Establish a protocol for communication	1. Establish an agreement about communication	1. Set the stage	1. Plan the setting	1. Setting up the interview
2. Establish what the patient/family already knows	2. Communication at diagnosis and later follow up	2. Engage the child at an opportune time	2. Elicit the information	2. Assess the knowledge and needs of the recipient	2. Assess the Patient's Perceptions
3. Determine how the information is to be handled	3. Communicate in a comfortable and private space	3. Explore what the child already knows	3. Give information	3. Choose appropriate strategies	3. Obtaining the patient's Invitation
4. Deliver the information	4. Communicate with both parents and others if desired	4. Explain information according to the child's developmental status and needs	4. Understand the recipient's perspective	4. Evaluate their understanding	4. Giving Knowledge/information to the patient
5. Respond to emotions	5. Hold a separate session with the child	5. Empathize with the child's emotions	5. End the encounter		5. Addressing the patient's Emotions with Empathy
6. Establish goals for treatment and care priorities	6. Solicit questions from the child and parents	6. Encourage the child that you will be there when needed			6. Strategy and Summary
7. Establish a plan	7. Communicate in a way sensitive to cultural differences				
	8. Share information about the diagnosis and plan for cure				
	9. Share information on lifestyle and psychological issues				
	10. Encourage the entire family to talk together				

Adapted from: Mack JW, Hinds PS. Chapter 19. Practical Aspects of Communication. Table 19-1. In: Wolfe J, Hinds PS, Sourkes BM, editors. *Textbook of Interdisciplinary Pediatric Palliative Care*. Elsevier/Saunders, Philadelphia, PA, 2011, pp. 181.



the impact of the information they are given. Third, nurses actively engage as advocates in palliative care planning by challenging the status quo and by assisting all invested parties to understand the overall patient care mission. This level of advocacy in which the child and family are given assistance with interpreting and understanding goals will lead to valid and shared decision making. The establishment of clear goals of care based on individual preferences and beliefs that are attainable within the structure of the clinical condition is the foundation upon which such decisions can be made. In addition, as described above, the ongoing multidimensional assessment performed by nurses facilitates their ability to identify distressing symptoms early and, therefore, mandates their advocacy for prompt attention to the relief of these symptoms.

### Assessing the needs of the child and family

In establishing unique, realistic goals and prioritization of care, a clear and accurate assessment of the needs of the child and family is essential. Parental engagement in such a process is fundamentally important and should be encouraged. Therefore, investigators and clinicians have begun to develop tools to assist in assessing parental engagement in decision making for seriously ill children during palliative care consultations. Kearney and Byrne, in the initial stages of development of the Parental Engagement Scale, described a conceptual model of parental engagement organized into three dimensions: information-centered dialogue, insightful participation, and achievement of a collaboratively agreed-upon plan.<sup>50</sup> Models such as this are instrumental in establishing a needs-based multidimensional plan of care.

As described above, the palliative care needs of children with life-threatening cancer and their families include physical, emotional, social and spiritual elements and a focus on enhancement of quality of life for the child and support for the family. The care burden can have an effect on all aspects of family life. Studies have described a range of experiences that families have encountered when caring for a child with a life-threatening malignancy; these include a lack of symptom control and pain relief in the child,<sup>3</sup> a feeling that the family's concerns are not being taken seriously,<sup>51</sup> poor communication between family

members and professionals,<sup>40</sup> as well as social, financial, and mental and physical health repercussions on the entire family.<sup>52,53</sup>

### The prevention and relief of pain and suffering

To best impact the lack of symptom control and pain relief, focused assessment of physical and emotional symptomatology is vital. Numerous, widely accepted pain scales (eg, Faces Pain Scale, FLACC, Oucher, Wisconsin) are available to assess and attempt to objectify pain among pediatric patients. The oncology nurse should have knowledge of the instruments used in their setting including a clear understanding of the meaning of the scores across a range of ages. Nurses can work to develop evidence-based practice protocols that incorporate the assessment indices produced by the use of these instruments. In addition, similar assessment of other distressing symptoms is equally important. The BREATH AIR mnemonic provides a measure to assess the most common causes of dyspnea and the initial steps in treatment (Table 2).

As described above, the assessment and frequent reassessment of pain and other symptoms is pivotal to quality palliative care, as unrelieved pain and suffering in a child with cancer commonly impacts the quality of life experienced by both the child and the family.<sup>54</sup> The acknowledgement and treatment of such symptoms is an area in which nursing may have a substantial impact. When parents perceive their child as suffering, they often feel helpless. By providing interventions to the family aimed at treating the source of suffering associated with cancer in children, nurses can empower parents with the ability to do something for their child. Empowering the family to have an active role in such an integral component of care as pain relief, may have far-reaching, positive effects. It may not only help the child physically, but it can also help the family emotionally.<sup>55</sup> The pediatric pain literature now clearly demonstrates that there is no such thing as “a little stick”; the effects of underdiagnosed and undertreated pain as well as unrelieved procedural pain are long-lasting.<sup>56,57</sup> The same may apply to many other symptoms yet to be studied in this manner. Symptom management and attention to the suffering of children who are dying must be comprehensive.<sup>58</sup> Equally important, relief of pain and suffering facilitates the capacity of both the child

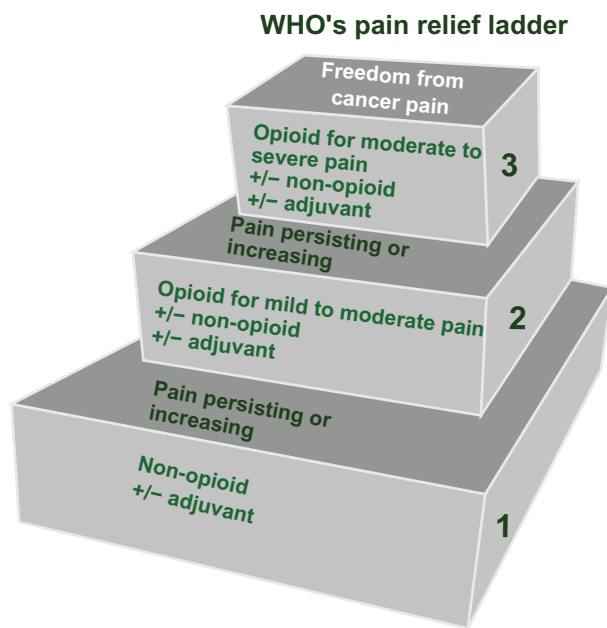
**Table 2.** Specific causes and treatments for dyspnea.

	<b>Cause</b>	<b>Treatment</b>
<b>B</b>	Bronchospasm	Consider nebulized albuterol and ipratropium and/or an inhaled steroid. Systemic steroids can be useful in cases of superior vena cava obstruction or tumor mass effect in the lung.
<b>R</b>	Rales	If a patient is volume overloaded, reduce or stop intravenous fluids and artificial feeding. Diuretics may be helpful, particularly when cardiac output is low. If pneumonia appears likely, consider a trial of antibiotics based on the goals of care, prognosis, and ability to take oral versus intravenous administration.
<b>E</b>	Effusions	Thoracentesis may be effective, and if the effusion recurs, pleurodesis or indwelling chest-tube drainage may be appropriate based on goals of care and a life expectancy of at least several weeks to months.
<b>A</b>	Airway obstruction, aspiration	Make sure that tracheostomy appliances are cleaned regularly. If aspiration of food is likely, purée solids and thicken liquids with cornstarch. Educate the family about how to position the patient during feeding. Suction the patient when appropriate.
<b>T</b>	Thick secretions	If the cough reflex is still strong, loosen thick secretions with nebulized saline and guaifenesin. If the cough is weak, treat thin secretions with atropine, 1% ophthalmic solution; topical scopolamine patches behind the ear(s) every 3 days; or glycopyrrolate every 3 hours as needed.
<b>H</b>	Hemoglobin low	A blood transfusion may add energy and reduce dyspnea for a few weeks. <sup>a</sup> The clinician needs to discuss the clinical status and goals with the patient and family to help determine the potential benefits versus relative burden of the transfusion, taking into consideration the etiology (and speed of recurrence) of the anemia.
<b>A</b>	Anxiety	Sitting upright, using a bedside fan, listening to calming music, and practicing relaxation techniques can be effective. Skillful counseling and a calming clinician may also be helpful. When chronic anxiety is a trigger for dyspnea, clonazepam or antidepressants may be useful. Important to note, dyspnea is a potent trigger for anxiety and may best be treated with opioids first and then a benzodiazepine. If the opioid dosage is limited by drowsiness, reduce the benzodiazepine dosage and then attempt to increase the opioid dosage.
<b>I</b>	Interpersonal issues	Social and financial problems contribute to anxiety and dyspnea. Counseling and interaction with social workers and other members of the interdisciplinary team may bring relief. When family relationships exacerbate the problem, a few days spent in a peaceful, home-like hospice inpatient unit may help to relieve the patient's symptoms.
<b>R</b>	Religious concerns	Although faith or an experience of the transcendent can bring profound comfort, some beliefs, such as "God is punishing me" or "God will heal me if I have enough faith" can precipitate or exacerbate dyspnea. Take the time to listen with full attention and presence, encouraging the patient to explore ways to reconnect and relieve existential burden. Coordinate treatment with the patient's spiritual adviser, chaplain, counselor, other healthcare professionals, and family members.

<sup>a</sup>Gleeson C, Spencer D. Blood transfusion and its benefits in palliative care. *Palliat Med*. 1995;9:307–13.

Table adapted with permission from: *UNIPAC 4: Managing Nonpain Symptoms*, by Tucker R, Nichols A. In: Storey CP, editor. *UNIPAC: A Resource for Hospice and Palliative Care Professionals*. 4th ed, 2012, Glenview, IL, American Academy of Hospice and Palliative Medicine. ©2012 by American Academy of Hospice and Palliative Medicine. Adapted with permission.





**Figure 2.** World Health Organization analgesic ladder. World Health Organization. <http://www.who.int/cancer/palliative/painladder/en/>. Accessed Mar 2, 2012.

and the family to be as fully present to each other as possible, rather than having attention distracted by distress over untreated symptoms.

Nearly all children with cancer experience some pain in the course of their illness, and this can worsen considerably at the end of life. Fortunately, with effective and prompt intervention, the pain can be controlled in the majority of patients.<sup>59</sup> There have been many efforts to improve education for physicians and nurses on pain management strategies in children, yet children continue to be undermedicated for their pain.<sup>60</sup> The current standard for treating children's cancer pain follows the World Health Organization's

**Table 3.** Basic premises of effective pediatric pain management.

- Pain medications should be scheduled, and not administered on an as needed basis.
- The most acceptable route of pain medication delivery for the patient should be utilized.
- Adjuvants (e.g. anti-epileptic medications and antidepressants for neuropathic pain) should be used to augment pain control.
- Side effects should be anticipated and treated aggressively.
- Pain can manifest in many ways including minimal or no evidence of physical discomfort.
- Pain can change over time and it is critical to reassess.

analgesic ladder, which outlines a strategy for tailoring the pain interventions to the child's level of reported pain (Fig. 2).<sup>61</sup> Children's pain should be assessed frequently and medications adjusted as necessary. The child's self-report of pain should be solicited whenever feasible and should be considered of ultimate importance. Although a detailed description of pain management is beyond the scope of this review, a few basic principles merit comment (Table 3). First, pain medications should be scheduled and not administered solely on an as needed basis. Second, there are many routes to administer an opioid; the simplest and most acceptable route for the patient should be utilized. Third, adjuvants such as anti-epileptic medications and antidepressants for neuropathic pain should be used to facilitate pain control. Fourth, side effects should be anticipated and treated aggressively. It can be assumed that any patient receiving chronic opioid therapy will develop constipation, and, therefore, a bowel regimen should be implemented coincident with the start of the opioid therapy. Fifth, pain can manifest in many ways including crying, withdrawal, aggression, fear of touch, and fear of movement. Some children with pain will exhibit minimal or no evidence of physical discomfort. Finally, pain can change over time and it is critical to reassess. The oncology nurse can be invaluable in ensuring appropriate analgesia by adhering to these principles, identifying subtle signs and symptoms of pain expression, and by detecting changes in pain and advocating for additional diagnostic tests and/or changes in therapy.

In addition, children with cancer frequently require very high doses of opioids to control pain. This may occur for several reasons. Children exposed to opioids for long periods of time develop tolerance to the drug and, therefore, require higher doses of the opioid to maintain the same level of pain relief. It is important to note that this is the result of tolerance and not addiction; addiction is a psychological dependence on the effects of the opioids. This distinction may be helpful to some families who worry about the potential for addiction. Concern for addiction should not be a factor in managing terminal pain in children. Furthermore, disease progression may also lead to pain requiring very high doses of opioids.<sup>62,63</sup> One point to emphasize is that there is no maximum dose of opioid that can be given to control pain; opioids are for the most part without ceiling effects.<sup>61</sup> A ceiling effect, applicable



to many medications, refers to the concept that after a certain dose of medication, there is no additional benefit but merely toxicity. This is not true for opioids: the higher the dose of opioid, the more effect that can be anticipated. In this way, opioid dosing is not limited by a specific dose but rather by dose-limiting side effects including constipation, nausea, sedation, myoclonus, and respiratory suppression. This is an important concept of palliative care pain management, as frequently (and appropriately) medical staff are uncomfortable administering doses of opioids above their usual level of practice.<sup>61</sup> Frequently, medical staff are concerned and fear that high dose opioids, with the inherent potential for significant side effect, may hasten a child's death. Available data would not appear to support this contention. Moreover, in end-of-life care, when the goal for comfort is the top priority, the principle of double effect addresses such concerns. According to the principle of double effect, an action that has one good (intended) effect and one potentially bad (unintended, but foreseeable) effect is permissible, if the following conditions are met: (1) the action itself must be good or indifferent, with only the good consequences of the action sincerely intended, (2) the good effect must not be produced by the bad effect, and (3) there must be a compelling reason for permitting the foreseeable bad effect to potentially occur.<sup>64</sup> This well-vetted approach provides an ethical standard that supports the use of interventions intended to relieve pain and suffering even though there is a foreseeable possibility that death may be hastened.<sup>65</sup> In cases in which the child is terminally ill and in severe pain, using large doses of opioids and sedatives to manage pain is justified when no other treatment options are available that would both relieve the pain and make the risk of death less likely.<sup>66</sup> In these cases, specialized palliative care consultation is recommended.

In addition to medications, non-pharmacologic interventions may also reduce the perception of pain. They may decrease the amount of pain medication that is needed thereby reducing unwanted side effects. These interventions include providing soothing surroundings, avoiding excessive lighting, and ensuring a pleasant room temperature and even pleasant smells in the room. Other techniques such as music therapy,<sup>66</sup> distraction, and guided imagery should be combined with medications to provide the child and family strategies to control pain.<sup>67</sup> Often families will have insight into

the things that comfort their child, and this input should be encouraged, as it not only helps the child but may also provide the family comfort.<sup>68</sup> Better bereavement outcomes (including enhanced family cohesiveness as well as decreased anxiety, stress, and depression) have been reported by parents who were actively involved in the care of their child.<sup>69</sup> Even simple interventions such as placing all commodities within easy reach for the child can contribute to a child's sense of comfort; attentiveness to these details can add much to the quality of nursing care at the end of life. Other simple measures that the bedside nurse may employ to minimize suffering for children with cancer include the use of gentle touch and avoidance of pressure on painful areas when required to perform physical procedures. Routine nursing care at the end of life can and should be limited to essential needs.<sup>70</sup> This latter point is easily overlooked in the hospital setting where, for example, measuring vital signs frequently is a matter of routine and policy.

### Prevention and relief of other symptoms

In addition to pain, children experience a variety of other symptoms that may compromise their quality of life during the terminal course of their illness. In a landmark paper, Wolfe described the most commonly reported symptoms of pediatric oncology patients at the end of life.<sup>60</sup> Fatigue was the most commonly reported symptom followed closely by pain, dyspnea, and anorexia. Fatigue, pain and dyspnea were the symptoms most commonly associated with suffering. Therefore, the practitioner providing palliative care to pediatric oncology patients should both anticipate, and specifically address the goals related to the prevention and/or treatment of these symptoms.<sup>71</sup> Each of these symptoms should be aggressively managed with appropriate medications and non-pharmacologic interventions including repositioning, relaxation, and massage. For example, morphine and a fan blowing air on a child's face can be very effective at reducing dyspnea. As with pain medicines, it is important to ensure that medications are scheduled for those symptoms such as constipation, nausea and vomiting that are likely to be persistent rather than episodic.

### Identification, Prevention, and Relief of Fear

There are many other sources of suffering present throughout a child's battle with cancer that are



accentuated at the end of life. For example, there is often an unspoken anxiety related to the fear of dying and/or the dying process. This anxiety will be experienced by both the child and the family; they will share some similar fears and worries, but others will be quite unique.<sup>72</sup> Identifying the specific fears and fostering candid discussion of them will allow the oncology nurse to minimize the suffering associated with this anxiety as much as possible. In addition, the fear of being alone in the face of death is often a contributor to anxiety.<sup>73,74</sup> By reassuring the patient that he or she will not be alone, and by creating an environment that avoids isolation, the bedside nurse can combat such worries. The ability of the oncology nurse to facilitate an atmosphere that allows loved ones to be present, encourages candid expression of feelings, and provides a sense of closeness and understanding among family members will do much to minimize the fears associated with dying.

Fear may also culminate in a range of emotional expressions on the part of the child that may be disturbing to families, particularly if they are not prepared. These assertions may include emotional lability,

aggression, and expressions of anger, depression, and withdrawal. Simply understanding that such expressions are not unexpected or abnormal may ease anxiety for the family and facilitate better coping. The oncology nurse may provide further reassurance by both practicing and introducing families to the concepts of active listening, simple relaxation, and therapeutic touch. In addition, the bedside nurse can structure the hospital or home environment to allow for maximum control and independence within the limitations imposed by the developmental level and physical condition of the child. Nurses can also mitigate the suffering of anxiety by explaining all procedures and therapies, detailing the physical effects the child is likely to experience, and answering all questions in a candid manner.

### Additional Areas of Concern

In addition to addressing the physical and emotional needs of the pediatric palliative care patient, the oncology nurse may foster a higher quality of life for the child, parents, and siblings in a number of other ways (Table 4). For example, it can be extremely helpful to facilitate appropriate spiritual care in accordance

**Table 4.** Dimensions of palliative care needs.

Needs	Child/adolescent	Parent/caregiver	Sibling
Symptom management	Nausea and vomiting Pain Anxiety Fatigue Dyspnea	Strategies for specific symptom relief Strategies to deal with changes in child activity level	Strategies to assist with symptom relief
Service and education	Goal setting: life prolonging/alleviation of suffering Dealing with emotions such as anger, guilt, frustration	Goal setting: life prolonging/alleviation of suffering Care coordination Knowing to whom to direct questions Access to health care team How to talk to child/sibling about death/dying Dealing with emotions such as denial, anger, guilt, and frustration Financial support	Dealing with emotions such as denial, anger, guilt, and frustration
Respite	Relief from focus on cancer and treatment	Relief from caregiving	Relief from daily focus on ill sibling, and isolation
Spiritual support	Hopefulness	Hopefulness Legacy making	Hopefulness Legacy making



with family's beliefs, affiliations, and desires. In addition, addressing components and manifestations of the grieving process including anticipatory grief and differences among genders and ages may provide reassurance, understanding, and comfort. Enlisting grief-counseling services when available and needed may be useful. Nurses can also partner with child life specialists, music therapists, and physical therapists to facilitate a child's or sibling's expression of emotions through art, music, or play activities. Siblings often feel isolated and displaced as parents understandably devote much of their time to the care and comfort of the dying child. Siblings may become resentful of their ill sibling and begin to feel guilty or ashamed about such feelings.<sup>75</sup> This may obviously become an important source of suffering for the sibling, and ultimately, for the entire family. Nurses can assist by helping the parents identify ways to involve siblings in the caring process. Parents should also be encouraged to schedule time to spend with the other children, and nursing can help identify a family member or trusted friend who can sit with the ill child.

## Conclusion

In summary, the early initiation of palliative care has been associated with numerous beneficial outcomes with no identified harm or increased medical costs to date for both the child and the family. These benefits include longer survival, improved symptom control, enhanced quality of life, and decreased caregiver burden. As such, and in accordance with the doctrine of many prestigious professional societies, palliative care should be administered concurrently with curative therapy in all children with life-limiting illnesses. This is particularly true for the pediatric patient with cancer. Clear, realistic, and objective treatment goals must be established for such care to be effective. The pediatric oncology nurse is positioned perfectly to assist the patient/family in identifying such goals, advocating for these goals with the medical team, and ensuring that these goals are consistently adhered to across all medical services. In addition, effective palliative care attempts to alleviate the physical, emotional, social, and spiritual suffering associated with life-limiting illness. The oncology nurse is vital in identifying these various forms of suffering, advocating for and administering effective therapy, and assessing the response to such therapies. Given that palliative

care is not a unique service as much as a philosophy of care, it is imperative that the pediatric oncology nurse acquire a basic understanding of palliative care principles as well as the core competencies and skills required to administer this fundamental therapy.

## Author Contributions

Conceived and designed the experiments: Not applicable. Analysed the data: Not applicable. Wrote the first draft of the manuscript: SLD, RFT. Contributed to the writing of the manuscript: SLD, CT, CA, RCB, RFT. Agree with manuscript results and conclusions: SLD, CT, CA, RCB, RFT. Jointly developed the structure and arguments for the paper: SLD, CT, CA, RCB, RFT. Made critical revisions and approved final version: SLD, CT, CA, RCB, RFT. All authors reviewed and approved of the final manuscript SLD, CT, CA, RCB, RFT.

## Funding

Author(s) disclose no funding sources.

## Competing Interests

Author(s) disclose no potential conflicts of interest.

## Disclosures and Ethics

As a requirement of publication author(s) have provided to the publisher signed confirmation of compliance with legal and ethical obligations including but not limited to the following: authorship and contributorship, conflicts of interest, privacy and confidentiality and (where applicable) protection of human and animal research subjects. The authors have read and confirmed their agreement with the ICMJE authorship and conflict of interest criteria. The authors have also confirmed that this article is unique and not under consideration or published in any other publication, and that they have permission from rights holders to reproduce any copyrighted material. Any disclosures are made in this section. The external blind peer reviewers report no conflicts of interest. Provenance: the authors were invited to submit this paper.

## References

1. Schulman-Green D, McCorkle R, Cherlin E, et al. Nurses' communication of prognosis and implications for hospice referral: A study of nurses caring for terminally ill hospitalized patients. *Am J Crit Care*. 2005;14:64-70.
2. End-of-Life Nursing Education Consortium. Fact Sheet. Available from: <http://www.aacn.nche.edu/elneec/about/factsheet>. Published 2011.





3. 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;26:1717–23.
4. Himmelstein BP, Hilden JM, Boldt AM, Weissman D. Pediatric Palliative Care. *N Engl J Med*. 2004;350:1752–62.
5. American Academy of Pediatrics: Committee on Bioethics and Committee on Hospital Care: Palliative care for children. *Pediatrics*. 2000;106:351–7.
6. 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.
7. Mazanec P, Daly BJ, Pitorak E, et al. A new model of palliative care for oncology patients with advanced disease. *J Hosp Palliat Nurs*. 2009;11:324–31.
8. Bakitas M, Lyons KD, Hegel MT, et al. The project ENABLE II randomized controlled trial to improve palliative care for rural patients with advanced cancer: baseline findings, methodological challenges, and solutions. *Palliat Support Care*. 2009;7:75–86.
9. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363:733–42.
10. Higginson IJ, Finlay IG, Goodwin DM, et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Manage*. 2003;25:150–68.
11. Meyers FJ, Carducci M, Loscalzo MJ, et al. Effects of a problem-solving intervention (COPE) on quality of life for patients with advanced cancer on clinical trials and their caregivers: simultaneous care educational intervention (SCEI): linking palliation and clinical trials. *J Palliat Med*. 2011;14:465–73.
12. Chow K, Coyle N. Providing Palliative Care to Family Caregivers Throughout the Bone Marrow Transplantation Trajectory: Research and Practice: Partners in Care. *J Hosp Palliat Nurs*. 2011;13:7–13.
13. Smith TJ, Temin S, Alesi ER, et al. American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care. *J Clin Oncol*. 2012;30:880–7.
14. Johnston DL, Vadeboncoeur C. Palliative care consultation in pediatric oncology. *Support Care Cancer*. 2012;20:799–803.
15. Zhukovsky DS, Herzog CE, Kaur G, et al. The impact of palliative care consultation on symptom assessment, communication needs, and palliative interventions in pediatric patients with cancer. *J Palliat Med*. 2009;12:343–9.
16. Baker JN, Hinds PS, Spunt SL, et al. Integration of palliative care practices into the ongoing care of children with cancer: Individualized care planning and coordination. *Pediatr Clin North Am*. 2008;55:223–50.
17. Baker JN, Kane JR, Rai S, Howard SC, Hinds PS; PCS Research Working Group. Changes in medical care at a pediatric oncology referral center after placement of a do-not-resuscitate order. *J Palliat Med*. 2010;13:1349–52.
18. Nelson JE, Cortez TB, Curtis JR, et al. Integrating Palliative Care in the ICU: The Nurse in a Leading Role. *J Hosp Palliat Nurs*. 2011;13: 89–94.
19. 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;284:2469–75.
20. Ries LA, Harkins D, Krapcho M, et al. *SEER Cancer Statistics Review, 1975–2003*. Bethesda, MD: National Cancer Institute; 2006.
21. Hunger SP, Raetz EA, Loh ML, Mullighan CG. Improving outcomes for high-risk ALL: translating new discoveries into clinical care. *Pediatr Blood Cancer*. 2011;56:984–93.
22. Nazemi KJ, Malempati S. Emergency department presentation of childhood cancer. *Emerg Med Clin North Am*. 2009;27:477–95.
23. Sung L, Klaassen RJ, Dix D, et al. Parental optimism in poor prognosis pediatric cancers. *Psychooncology*. 2009;18:783–8.
24. Mack JW, Cook EF, Wolfe J, et al. Understanding of prognosis among parents of children with cancer: parental optimism and the parent-physician interaction. *J Clin Oncol*. 2007;25:1357–62.
25. Docherty SL, Miles MS, Brandon D. Searching for “the dying point:” providers’ experiences with palliative care in pediatric acute care. *Pediatr Nurs*. 2007;33:335–41.
26. Bakitas M, Lyons KD, Hegel MT, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *JAMA*. 2009;302:741–9.
27. Emanuel LL, von Gunten CF, Ferris FD. Module 7. Goals of care. In: *The Education for Physicians on End-of-life Care (EPEC) Curriculum*. Chicago, IL: Institute for Ethics, American Medical Association; 1999.
28. Feudtner C. Collaborative communication in pediatric palliative care: A foundation for problem solving and decision-making. *Pediatr Clin North Am*. 2007;54:583–607.
29. Committee on Palliative and End-of-Life Care for Children and their Families. *When Children Die: Improving Palliative and End-of -Life Care for Children and their Families*. Washington, DC: National Academy Press; 2003.
30. Masera G, Spinetta JJ, Jankovic M, et al. Guidelines for assistance to terminally ill children with cancer: a report of the SIOP Working Committee on psychosocial issues in pediatric oncology. *Med Pediatr Oncol*. 1999;32:44–8.
31. Medicare and Medicaid Programs: hospice conditions of participation; final rule. In: *Centers for Medicare and Medicaid Services*. 42 CFR Part 418. Baltimore, MD: US Dept of Health and Human Services; 2008.
32. Medicare Hospice Benefits. In: *Centers for Medicare and Medicaid Services*. Baltimore, MD: US Dept of Health and Human Services; 2010.
33. Ferrell B, Connor SR, Cordes A, et al. National Consensus Project for Quality Palliative Care Task Force Members. The national agenda for quality palliative care: The National Consensus Project and the National Quality Forum. *J Pain Symptom Manage*. 2007;33:737–44.
34. Tamburro RF, Shaffer ML, Hahnen NC, Felker P, Ceneviva GD. Care goals and decisions for children referred to a pediatric palliative care program. *J Palliat Med*. 2011;14:607–13.
35. Kaldjian LC, Curtis AE, Shinkunas LA, Cannon KT. Goals of care toward the end of life: A structured literature review. *Am J Hosp Palliat Care*. 2008;25:501–11.
36. World Health Organization. WHOQOL-BREF: *Introduction, Administration, Scoring and Generic Version of the Assessment*. Field Trial Version. Geneva, Switzerland: World Health Organization, Programme on Mental Health; 1996.
37. Tubbs-Cooley HL, Santucci G, Kang TI, et al. Pediatric nurses’ individual and group assessments of palliative, end-of-life, and bereavement care. *J Palliat Med*. 2011;14:631–7.
38. Hinds PS, Drew D, Oakes LL, et al. End-of-life care preferences of pediatric patients with cancer. *J Clin Oncol*. 2005;23:9146–54.
39. Thompson LA, Knapp C, Madden V, Shenkman E. Pediatricians’ perceptions of and preferred timing for pediatric palliative care. *Pediatrics*. 2009;123:e777–82.
40. Davies B, Sehring SA, Partridge JC, et al. Barriers to palliative care for children: Perceptions of pediatric health care providers. *Pediatrics*. 2008; 121:282–8.
41. von Gunten CF, Ferris FD, Emanuel LL. The patient-physician relationship. Ensuring competency in end-of-life care: communication and relational skills. *JAMA*. 2000;284:3051–7.
42. Masera G, Chesler MA, Jankovic M, et al. SIOP Working Committee on psychosocial issues in pediatric oncology: guidelines for communication of the diagnosis. *Med Pediatr Oncol*. 1997;28:382–5.
43. Beale EA, Baile WF, Aaron J. Silence is not golden: communicating with children dying from cancer. *J Clin Oncol*. 2005;23:3629–31.
44. Makoul G. The SEGUE Framework for teaching and assessing communication skills. *Patient Educ Couns*. 2001;45:23–34.
45. Garwick AW, Patterson J, Bennett FC, Blum RW. Breaking the news. How families first learn about their child’s chronic condition. *Arch Pediatr Adolesc Med*. 1995;149:991–7.
46. Baile WF, Buckman R, Lenzi R, et al. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist*. 2000;5:302–11.
47. Hammes BJ, Klevan J, Kempf M, Williams MS. Pediatric advance care planning. *J Palliat Med*. 2005;8:766–73.
48. Stewart JL, Pyke-Grimm KA, Kelly KP. Making the Right Decision for My Child With Cancer: The Parental Imperative. *Cancer Nurs*. Jan 30, 2012. [Epub ahead of print.]





49. Adams JA, Bailey DE Jr, Anderson RA, Docherty SL. Nursing Roles and Strategies in End-of-Life Decision Making in Acute Care: A Systematic Review of the Literature. *Nurs Res Pract*. 2011;2011:527834. Epub Oct 2, 2011.
50. Kearney JA, Byrne MW. Planning with parents for seriously ill children: Preliminary results on the development of the Parental Engagement Scale. *Palliative and Supportive Care*. 2011;9:367–76.
51. Hilden J, Ezekiel E, Fairclough D, et al. Attitudes and practices among paediatric oncologists. Regarding end-of-life care: Results of the 1998 American Society of Clinical Oncology Survey. *J Clin Onc*. 2001;19:205–12.
52. Monterosso L, Kristjanson LJ, Aoun S, Phillips MB. Supportive and palliative care needs of families of children with life-threatening illnesses in Western Australia: evidence to guide the development of a palliative care service. *Palliat Med*. 2007;21:689–96.
53. Monterosso L, Kristjanson LJ. Supportive and palliative care needs of families of children who die from cancer: an Australian study. *Palliat Med*. 2008;22:59–69.
54. Miller E, Jacob E, Hockenberry MJ. Nausea, pain, fatigue, and multiple symptoms in hospitalized children with cancer. *Oncol Nurs Forum*. 2011;38:e382–93.
55. Pöder U, Ljungman G, von Essen L. Parents' perceptions of their children's cancer-related symptoms during treatment: a prospective, longitudinal study. *J Pain Symptom Manage*. 2010;40:661–70.
56. Weisman SJ, Bernstein B, Schechter NL. Consequences of inadequate analgesia during painful procedures in children. *Arch Pediatr Adolesc Med*. 1998;152:147–9.
57. Berde CB, Sethna NF. Analgesics for the treatment of pain in children. *N Engl J Med*. 2002;347:1094–103.
58. Goldman A, Hewitt M, Collins GS, et al. Symptoms in children/young people with progressive malignant disease: United Kingdom Children's Cancer Study Group/Paediatric Oncology Nurses Forum survey. *Pediatrics*. 2006;117:e1179–86.
59. Meuser T, Pietruck C, Radbruch L, et al. Symptoms during cancer pain treatment following WHO-guidelines: a longitudinal follow-up study of symptom prevalence, severity and etiology. *Pain*. 2001;93:247–57.
60. Wolfe J, Grier HE, Klar N, et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med*. Feb 3, 2000;342(5):326–33.
61. World Health Organization. *Cancer Pain and Relief and Palliative Care in Children*. Geneva, Switzerland: World Health Organization; 1998.
62. Jones PD, Wilkinson IA. Massive opioid requirements in children with disseminated central nervous system disease. *J Pediatr*. 1996;128:864–5.
63. Collins JJ, Grier HE, Kinney HC, Berde CB. Control of severe pain in children with terminal malignancy. *J Pediatr*. 1995;126:653–7.
64. Rousseau P. Ethical and legal issues in palliative care. *Prim Care*. 2001;28:391–400.
65. Hawryluck LA, Harvey WR. Analgesia, virtue, and the principle of double effect. *J Palliat Care*. 2000;16(Suppl):S24–30.
66. Kemper KJ, Danhauer SC. Music as therapy. *South Med J*. 2005;3:282–8.
67. Lambert S. Distraction, imagery, and hypnosis techniques for management of children's pain. *J Child Fam Nurs*. 1999;2:5–15.
68. Anderson T, Davis C. Evidence-based practice with families of chronically ill children: a critical literature review. *J Evid Based Soc Work*. 2011;8:416–25.
69. Goodenough B, Drew D, Higgins S, et al. Bereavement outcomes for parents who lose a child to cancer: are place of death and sex of parent associated with differences in psychological functioning? *Psychooncology*. 2004;13:779–91.
70. Foster TL, Lafond DA, Reggio C, Hinds PS. Pediatric palliative care in childhood cancer nursing: from diagnosis to cure or end of life. *Semin Oncol Nurs*. 2010;26:205–21.
71. Hellsten MB, Hockenberry M, Lamb D, et al. *End-of-life Care for Children*. Austin, TX; Texas Cancer Council; 2000.
72. Theunissen JM, Hoogerbrugge PM, van Achterberg T, Prins JB, Vernooij-Dassen MJ, van den Ende CH. Symptoms in the palliative phase of children with cancer. *Pediatr Blood Cancer*. 2007;49:160–5.
73. van Breemen C. Using play therapy in paediatric palliative care: listening to the story and caring for the body. *Int J Palliat Nurs*. 2009;15:510–4.
74. Slaughter V, Griffiths M. Death understanding and fear of death in young children. *Clin Child Psychol Psychiatry*. 2007;12:525–35.
75. Murray JS. Siblings of children with cancer: a review of the literature. *J Pediatr Oncol Nurs*. 1999;16:25–34.