

# Journal of Pediatric Oncology Nursing

<http://jpo.sagepub.com/>

---

## Understanding Pediatric Palliative Care : What It Is and What It Should Be

Eileen R. O'Shea and Robin Bennett Kanarek  
*Journal of Pediatric Oncology Nursing* 2013 30: 34  
DOI: 10.1177/1043454212471725

The online version of this article can be found at:  
<http://jpo.sagepub.com/content/30/1/34>

---

Published by:



<http://www.sagepublications.com>

On behalf of:



ASSOCIATION of PEDIATRIC  
HEMATOLOGY/ONCOLOGY NURSES

[Association of Pediatric Hematology/Oncology Nurses \(APHON\)](#)

Additional services and information for *Journal of Pediatric Oncology Nursing* can be found at:

**Email Alerts:** <http://jpo.sagepub.com/cgi/alerts>

**Subscriptions:** <http://jpo.sagepub.com/subscriptions>


**Reprints:** <http://www.sagepub.com/journalsReprints.nav>

**Permissions:** <http://www.sagepub.com/journalsPermissions.nav>

>> [Version of Record](#) - Jan 31, 2013

[What is This?](#)

# Understanding Pediatric Palliative Care: What It Is and What It Should Be

Journal of Pediatric Oncology Nursing  
30(1) 34-44  
© 2013 by Association of Pediatric  
Hematology/Oncology Nurses  
Reprints and permission:  
sagepub.com/journalsPermissions.nav  
DOI: 10.1177/1043454212471725  
http://jpo.sagepub.com  


Eileen R. O'Shea, DNP, RN, CHPPN<sup>1</sup>, and Robin Bennett Kanarek, BSN, RN<sup>1</sup>

## Abstract

Advancing pediatric palliative care is desperately needed to support the physical, emotional, cultural, spiritual, and psychosocial needs of children and families who live with life-threatening illnesses. Although educational resources and standards of practice related to this topic have been developed, dissemination and implementation of programs have been slow to progress. The purpose of this case study is to present the lived experiences of an adolescent with leukemia and his family to illustrate how health care providers may benefit from receiving enhanced palliative and end-of-life care education.

## Keywords

pediatric oncology, pediatric palliative care, stem cell transplant, psychological support, life-threatening illness

**Editor's Note:** The case study presented here tells the story of David Karanek, and his family. David, the son of coauthor Robin Kanarek, BSN, RN, and her husband, Joe, was diagnosed with acute lymphoblastic leukemia in 1995, at age 11. While remarkable strides have been made since then in the treatment of pediatric cancers, an often-fragmented health care system and insufficient attention to psychosocial aspects of the illness too often result in inadequate care for many patients and their families. Details of David's journey, and his family's, from the point of diagnosis illustrate how health care providers might benefit from improved education in pediatric palliative and end-of-life care.

## Introduction

More than a decade ago, the Children's International Project on Palliative/Hospice Services (ChIPPS) issued a white paper with recommendations to improve the care of children living with life-threatening conditions (National Hospice and Palliative Care Organization [NHPCO], 2001). Following this report, the Institute of Medicine (IOM) released *When Children Die: Improving Palliative and End of Life Care for Children and Their Families* (Field & Behrman, 2003), which provided empirical evidence that the US health care system was failing to meet the

physical, emotional, cultural, spiritual, and psychosocial needs of children with life-threatening illness and their families. Despite these calls to action, health care professionals have been slow to implement the recommended improvements in pediatric palliative and end-of-life care.

One reason for this gap in care is that the majority of health care providers lack formal education in palliative and end-of-life care for children. Education in several areas needs to be improved, including communication techniques that help forge better relationships between patients and providers, self-examination and reflection among health care providers, pain and symptom management, sensitivity to cultural and spiritual beliefs, and grief and bereavement care (see Box for a more detailed enumeration of needed educational improvements; Sahler, Frager, Levetown, Cohn, & Lipson, 2000; Wolfe, Hinds, & Sourkes, 2011).

---

<sup>1</sup>Fairfield University, Fairfield, CT, USA

## Corresponding Author:

Eileen R. O'Shea, DNP, RN, Fairfield University, 1073 North Benson Road, Fairfield, CT 06824-5195, USA  
Email: eoshea@fairfield.edu

### **Educational Improvements Needed to Advance Pediatric Palliative Care**

According to the experts in pediatric palliative care, including the American Academy of Pediatrics (2000) and the ChiPPS Workgroup (NHPCO, 2001), the educational areas that need improvement include the following: learning how to work within an interdisciplinary team; supporting the rights of patients living with life-threatening conditions and their families; communicating bad news and establishing compassionate goals of care; managing the uncertainty of illness; assisting with decision making related to life-sustaining interventions, including possible outcomes; treating pain and managing symptoms; using complementary and alternative therapies; assisting with anticipatory grief and bereavement; incorporating spiritual and cultural beliefs into care; including volunteers, community supports, and spiritual resources in meeting the complex needs of children and families; informing parents, community health care professionals, volunteers, respite workers, and school and community resources to enhance continuity of care; and interpreting pediatric palliative care research and informing health economics of palliative care.

In an effort to address the concerns raised by the ChiPPS and IOM reports, health care professionals have responded by expanding educational resources (see Table 1) and developing new policies, practice guidelines (such as the 2009 Clinical Practice Guidelines for Quality Palliative Care, discussed below), and specialty certifications for nurses and physicians (Andreoni, Obrecht, & Bowden, 2007; Browning & Solomon, 2005).

### ***Pediatric Palliative Care Defined***

Confusion about the meaning of palliative care and the ways in which it differs from hospice care persists among health care providers and the public. Recent media reports on advance directives and end-of-life and palliative care have often added to the confusion and frequently imply that palliative care is administered only at the end of life, when all curative treatments have been exhausted. But this characterization misses the essence of palliative care.

The following provides a good illustration of the need for a clearer definition of palliative care and a broader understanding of its means and aims. A front page article in the *New York Times*, "At the End, Offering Not A Cure but Comfort" (Hartocollis, 2009), reported that several physicians—all palliative care specialists in New York City hospitals—believed there was a lack of agreement among clinicians about the best way to deliver bad news, such as a

cancer diagnosis, and expressed concern about possibly sending the message that they were "giving up on their patients," thereby diminishing hope. Responding in a letter to the editor, Gail Austin Cooney, MD, FAAHPM, president of the American Academy of Hospice and Palliative Care Medicine, commented:

The article presented a detailed, sensitive look at one aspect of palliative care—hospice care—but could leave the impression that palliative care is only for patients who are dying. That is not true. It can help patients who will live years after they receive a diagnosis of a life-threatening or chronic illness. Palliative care can help patients better tolerate treatments as they recover. (Cooney, 2009, p. A20)

Dr Cooney's response clarifies the goals of palliative care, which are not to diminish but to promote hope and better quality of life.

The ChiPPS offers a similar perspective, defining palliative care as follows:

Palliative care is the science and art of lessening physical, psychosocial, emotional, and existential suffering. Palliative care can benefit patients and families whether the overall goals of care are to cure, prolong life, maximize the quality of the life that remains, or ease the pain of bereavement. Thus, palliative care may be provided concurrently with, or as an alternative to, life-sustaining medical intervention. (NHPCO, 2001, p. 1)

The Clinical Practice Guidelines for Quality Palliative Care (National Consensus Project for Quality Palliative Care, 2009) suggest that palliative care enhances quality of life for patients and families and takes into consideration individual needs, preferences, values, and cultural and spiritual beliefs. Nurses, chaplains, social workers, psychologists, and physicians may provide this care (National Consensus Project for Quality Palliative Care, 2009). Furthermore, pediatric palliative care encompasses not only the child and family but also includes the extended community, which may include school nurses, counselors, teachers, classmates, teammates, and friends, who can serve as an important support system for the patient and family.

In contrast, adult hospice programs generally limit their care to patients who are expected to live for 6 months or less and have elected to forego curative treatment. These criteria are usually not appropriate for the pediatric population because it is difficult to determine prognosis and to estimate length of survival in children who live with life-threatening conditions (NHPCO, 2001). The uncertainty of prognosis often contributes to fragmented care and delays in referring patients and their families to supportive resources. Therefore,

**Table 1.** Pediatric Palliative and End-of-Life Care Education Resources

Resource	Sponsoring/Developing Group
End of Life Nursing Education Consortium- Pediatric Palliative Care Program (ELNEC-PPC)	American Association of Colleges of Nursing (AACN) City of Hope National Medical Center of Los Angeles
Initiative for Pediatric Palliative Care (IPPC)	Education Development Center, Inc (EDC) National Association of Children's Hospitals and Related Institutions (NACHRI) Society of Pediatric Nurses (SPN) Association of Medical School Pediatric Department Chairs (AMSPDC) New York Academy of Medicine (NYAM)
The Program in Palliative Care Education and Practice	Harvard Medical School, Center for Palliative Care
Education and Training Curriculum Pediatric Palliative Care	National Hospice and Palliative Care Organization
Children's Hospice International Program for All- Inclusive Care for Children and Their Families	Children's Hospice International Program (CHI-PACC)
Palliative Care and HIV/AIDS Training Curriculum	The Center for Palliative Care Education

Note: Adapted from Andreoni, Obrecht, and Bowden (2007) and Browning and Solomon (2005).

to best coordinate complex medical care and promote better quality of life for these children and their families, the American Academy of Pediatrics suggests that palliative care be instituted from the time of diagnosis through the trajectory of the child's life-threatening condition (American Academy of Pediatrics, 2000; Wolfe et al., 2011). It is essential that the interprofessional health care team provide well-coordinated, supportive, and compassionate integrative care, including continual priority-based assessment of the needs of the patient and family. This care should never be limited to the last 6 months of life.

## Case Study

David was playing with his younger sister, Sarah, in our kitchen before dinner. Suddenly and with no apparent cause, he fell down. I went to check on him and asked what happened; he said that his legs "buckled." Over the next several hours he began limping and complained that his hip was very sore. By the end of that week, he couldn't walk. Our pediatrician was perplexed. David had just turned 11 and had had a complete physical examination a week before. Everything had appeared normal. Now the ache in David's hip was intensifying every day and soon he was crying out in pain. Benign conditions were ruled out one by one. The pediatrician ordered a computed tomography scan. Six weeks after the onset of the mysterious pain, David's father, Joe, and I learned that the results of the scan were "suspicious." The pediatrician then referred us to a pediatric oncologist, who performed a bone marrow biopsy.

The biopsy indicated that David had acute lymphoblastic leukemia. The oncologist immediately sent David to a children's hospital to begin chemotherapy. David achieved remission within 3 weeks and, by mid January, he returned to school. For the next 2 years he endured an intensive chemotherapeutic regimen.

Three years after the initial diagnosis, things had more or less returned to normal. David achieved his Bar Mitzvah and won the principal's award on graduation from eighth grade. During the summer—with the approval and encouragement of his pediatric oncologist—David, then 15, went to sleep-away camp for a month. This was his first time away from home since his diagnosis, and he was nervous. So were his father and I. When he came home, we noticed that he was limping and supporting his hips with his hands. I took him to the oncologist's office the next day. His blood work was normal, but his mobility began to deteriorate. He could barely tolerate his first day as a freshman in high school. Within 2 hours the school nurse called, and when I arrived to pick him up, I noticed that David was pale and short of breath. I immediately brought him to the oncologist, where another bone marrow biopsy revealed that the disease had returned.

The medical team that had treated David initially determined that his body was too weak to endure long-term chemotherapy. The pediatric oncologist recommended that David be taken to a prominent children's hospital in another state to discuss a bone marrow transplant and a new treatment plan. We followed this advice immediately. Joe and I took David to a consultation with

the esteemed head of the bone marrow transplant team. Of course, we had high expectations and were eager to hear new recommendations.

The meeting did not go as we hoped it would. As soon as formal introductions were exchanged, the surgeon plunged into a discussion of the complications and mortality rates associated with the risky bone marrow transplant. I turned toward David, who had covered his ears with his hands; he was looking down and shaking his head in disbelief. Joe and I were aghast. How could such a highly skilled physician be so insensitive to the power of her words and the effect they might have on our young son?

We asked David whether he wanted to leave the room. He did. At the close of the meeting, Joe and I were bewildered. If the head of the transplant team could be so unaware of the effect of her words, then what could we expect from the rest of the clinicians we'd encounter there? We decided not to entrust our son's care to that institution.

### *Communicating With Patients and Families*

Our family's experience is not unusual. Health care professionals who care for children with life-threatening illness and their families may agree that communicating serious medical findings, prognoses, and treatment options is vital—parents need such information so they can make the best decisions concerning their child's care—yet, in presenting such information, clinicians are not always mindful of the emotional and psychological impact on the child and other family members. Moreover, research supports the idea that providers should take time to assess the family's understanding of the illness, determine when to engage the child in the conversation, and respect parents' wishes about what information to present to the child (Beale, Baile, & Aaron, 2005). To meet these standards, providers must be observant and take their cues from the child, parents, and other family members. They should be cognizant that families with a child who has a life-threatening illness often experience emotional anguish and—not having experienced such situations previously—may not have developed adequate coping mechanisms.

The importance of establishing open lines of communication between the patient, family, and physician has been well documented (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004; Mack et al., 2005; Meyer, Burns, Griffith, & Truog, 2002). In fact, communication guidelines have been developed to help health care providers conduct difficult conversations related to complex medical conditions and end-of-life care (Baile, et al., 2000; Beale et al., 2005; Garwick, Patterson, Bennett, & Blum, 1995; Levetown, 2008; Makoul, 2001; Masera et al., 1997; Von Gunten, Ferris, & Emanuel, 2000). For example, the SPIKES framework (Baile et al., 2000) provides a six-step method to help clinicians plan how to break bad news to patients and families: *setting up*

the interview, assessing the patient's *perception*, obtaining the patient's *invitation*, giving *knowledge* and information to the patient, addressing the patient's *emotions* with empathic responses, and strategy and *summary* (Baile et al., 2000). The meeting may occur once or several times, according to the patient's needs.

When applying the SPIKES framework, experts recommend that health care professionals involved in palliative and end-of-life care choose their words carefully, think before speaking, and frame their communications in terms that are both hopeful and realistic, even as the patient approaches death (End of Life Nursing Education Consortium [ELNEC-PPC], 2007). Furthermore, clinicians should practice having sensitive conversations before interacting with patients and families. While clinicians can mentally rehearse conversations before initiating them, the health care team should also regularly practice having these conversations in role-playing exercises. Such preparation should also be integrated into educational programs for future clinicians. The ability to instill hope in order to provide comfort and promote better quality of life for patients and their families is a vital goal of this practice.

### *Maintaining Hope*

Many parents of children who endure excruciating cancer treatment say that they draw their strength from hope. According to the End of Life Nursing Education Consortium, "in most cases parents remain hopeful for a miracle cure even until the time of death" (ELNEC-PPC, 2007, p. M1-23). In the *Oxford Textbook of Palliative Nursing* (2010), Sumner writes,

With the presence of hope, parents speak of being able to continue their care-giving responsibilities, having the strength to put one foot in front of the other, and being able to carry on in their day-to-day existence. Without hope, the burden of the child's impending death would be utterly paralyzing. (pp. 1015-1016)

We found this to be true in our own experience. My husband and I maintained hope that David would be cured, and this helped us cope throughout the course of his illness. Joe said,

Deep down, you are always aware of the possibility of your child succumbing to the disease. You do not, however, allow yourself to think that way, and therefore, hope is actually a standing belief, or almost a religious belief, that all this terrible process must logically end with a positive result.

Describing hope as a "religious belief" acknowledges that, for many people, there is an important spiritual aspect in caregiving, one that's often neglected by health care

providers. Recent research has documented the importance of talking with patients and their families about spiritual beliefs and concerns; such conversations may serve to identify important coping mechanisms and sources of emotional support (Feudtner, Haney, & Dimmers, 2003; Himmelstein, Hilden, Morstad Boldt, & Weissman, 2004; O'Shea, Wallace, Quinn Griffin, & Fitzpatrick, 2011). Conversations about spirituality need not be the sole province of pastoral care specialists; clinicians who have developed a trusting relationship with patients and families can also have these discussions (Himmelstein et al., 2004; Foster, Lafond, Reggio, & Hinds, 2010). Providing spiritual care may also involve assisting the child and family in the task of *redefining or affirming hope* and supporting belief systems that are already in place (Davies, Brenner, Orloff, & Worden, 2002; Foster et al., 2010).

Thus, clinical experts recommend helping the patient and family maintain hope during all phases of a child's life-threatening illness, even if the prognosis changes for the worse (Sumner, 2010). Holding on to hope may serve as a source of strength for parents, helping them continue to comfort and support their child and each other (Wolfe et al., 2011).

Holding onto hope is not only important to parents but also has implications for teenage patients. For example, a 1988 qualitative study by Hinds clarified the role of hopefulness in well and ill adolescents, showing that the latter may remain hopeful despite the seriousness of their illness and expand their hopefulness beyond themselves to focus on hope for others (Hinds, 1988). Based on these findings, Hinds defined adolescent hopefulness as "the degree to which an adolescent possesses a comforting or life sustaining, reality-based belief that a positive future exists for self or others" (p. 85). Although hope may shift from cure to comfort and better quality of life for patients and their families, the intention of health care providers should remain positive yet realistic (Sumner, 2010; Duncan, Spengler, & Wolfe, 2007).

Humor, too, has its place in maintaining hope. Reflecting on the experience of trying to help raise David's spirits, Joe said,

One way of dealing with the most difficult moments is, at times, black humor. Laughing at unpleasant procedures or their side effects is a rechanneling of energy and may create a feeling of us "defeating" all those bad things; if we can laugh at them, they can't hurt us.

### *Discussing Illness and Mortality*

During the entire course of David's illness and treatment, his father and I were always aware that he could lose his life. At the age of 11 and with no knowledge or experience of cancer, David didn't fully grasp the seriousness

of his illness; in fact, he was relieved when he learned his diagnosis. Finally, there was a name for the cause of his problems. When David's cancer recurred at age 15, his understanding was significantly more advanced. By this time he had learned about all the medications and their side effects. Devastated that he was going to have to undergo more treatments, he asked, "Why me? What did I do wrong?" I felt at a loss for words. I wasn't prepared to answer this question.

David endured more chemotherapy to achieve remission, and then underwent a stem cell transplant. For a month afterward he remained in strict isolation. Soon our usually even-tempered and amiable son was becoming depressed, easily agitated, and uncharacteristically confrontational. The members of the interdisciplinary team, which included oncologists, nurses, and a child psychiatrist, initially surmised that this was normal behavior for someone David's age who had been placed in isolation, but it was obvious by the second week that there was something more going on. His father and I again sought professional guidance.

The child psychiatrist spoke to him but was unable to coax him into sharing what was troubling him. David resented the psychiatrist's attempt to intervene and eventually "fired" him. When we asked the psychiatrist to try again, he refused. Meanwhile, Joe and I and the rest of the team members were becoming more concerned over David's mental state.

When we approached David's favorite physician to ask him to talk with our son, his body language telegraphed his discomfort. It was an uncomfortable moment for us, too. We felt that David needed professional help in dealing with his emotions, and we weren't qualified, ourselves, to handle this difficulty. But the physician didn't offer an explanation for his reluctance. We wondered how this highly skilled expert—one who could navigate through all of the medical complexities of treating cancer—could be so ill equipped in the face of a teenager's psychological struggle. With a sense of desperation, we pleaded with the physician until he relented.

Three hours later, mentally exhausted, the physician emerged from David's room and told us that our son had many questions about death and his own mortality. The physician didn't divulge the details, but it was obvious that the discussion was much needed. We hesitantly entered David's room, not knowing how he'd reacted to the emotionally sensitive conversation. We were astonished to find him smiling and calm, in a peaceful state of mind. He was ready to play a game!

Looking back on this interaction after David's death 6 months later, I was so grateful that he'd had the opportunity to have this discussion. Having such conversations, despite their difficulty, is crucial in easing psychological and emotional burdens and alleviating fears for both children and parents. Children typically want to know what

happens to them and to their family after death (Mack & Hinds, 2011). Children may not be comfortable having such sensitive conversations with their parents; they may sense that it would be too distressing and want to protect the parents' feelings. Therefore, a trusted clinician may be able to elicit a pediatric patient's innermost fears or concerns. Such conversations may need time to develop.

### *Self-Examination Among Health Care Providers*

Pediatric medical specialists report feelings of powerlessness, unfairness, lack of competence, and personal vulnerability when trying to deal with the death of children (Sahler et al., 2000; Yam, Rossiter, & Cheung, 2001). Clinical experts assert that providers' attitudes toward a child's death may be the greatest barrier that prevents or delays the patient's and family's access to expert palliative support resources (Sumner, 2010). A strategy to overcome this barrier includes self-examination through reflection. Sahler and colleagues (2000) describe the importance of educating health care providers in self-examination and reflective practice, using methods that include journal writing, standardized patient simulation and role play, and professional peer support groups. The benefits may include increased awareness of personal values and beliefs and a better understanding of how they affect the ability to give and receive information. Reflective practice may also lead to an increased willingness to "risk remaining emotionally engaged with dying children and their families" (Sahler et al., 2000, p. 576).

In the first 6 months after the transplant, David did well. In the seventh month, he developed graft-versus-host disease and was treated conservatively at home. Six weeks later, his treatment was intensified with intravenous prednisone, which further suppressed his immune system and left him vulnerable to infection. Soon after this treatment began, David experienced worsening symptoms and needed to be hospitalized. As long as we were with him, David remained calm and good-humored while coping with the treatments. Our fear was under control.

In the last 2 weeks of his life, David suffered seizures and severe respiratory distress. The health care team members suspected that David had contracted an aspergillus infection due to his immunocompromised state (a suspicion that was later confirmed by autopsy). Over the course of several days, David's oxygen levels declined and he required intubation to maintain a normal level, but even that intervention didn't change the fact that his vital organs were beginning to fail. David was heavily sedated. It was during this time that David was transferred into the pediatric intensive care unit and his condition deteriorated quickly. There was a noticeable change in the doctors' and

nurses' behavior and body language. They knew how serious the situation was. Tense and distant, they always hurried in and out of the room and avoided eye contact with Joe and me. They didn't speak to us; they spoke among themselves as if we weren't there. We sensed their fear that David was going to die, and this terrified us. I sensed that this was the beginning of the end.

I asked the chief resident what David's chances of survival were, and if he did survive, what kind of quality of life we could expect. The physician reluctantly admitted that if he survived, he would need several organ transplants and would be ridden with catastrophic health issues throughout the remainder of his life. Until then, none of the clinicians had initiated a conversation about the possibility of David not surviving, nor had anyone raised the question of his probable quality of life if he did survive. Once Joe and I understood the likely outcomes, we were able to come to a decision: we decided not to escalate care. The primary focus of care was to be supportive, with an emphasis on comfort and pain management. We also decided to forego cardiopulmonary resuscitation.

It takes the guidance of an educated, experienced professional to assist parents in making such difficult decisions. Ideally, the provider should outline options for families *before* a life-threatening event occurs. Possible negative patient outcomes, such as irreversible organ damage, need to be communicated to family members early on, so they'll have time to assimilate the information, ask questions, and clarify what's been stated. It should not be the responsibility of the parents to approach the clinicians to piece together this information.

Over the course of several hours on his last day, David's heartbeat began to get slower and slower until it finally stopped. Joe and I were at his bedside.

### *Partnerships and Presence*

Taking part in difficult conversations at the end of life is a challenge for both health care providers as well as for the patient and family. It's vital that providers maintain open communication and sensitive listening to support the patient and family, especially in times of great duress. They must also be capable of bearing witness to a dying child and a grieving family. Simple presence—staying close and saying nothing—can sometimes provide more comfort than words (ELNEC-PPC, 2007; Hurwitz, Duncan, & Wolfe, 2004).

Planning the goals of care with the child and family at the center, particularly when the child has a life-threatening illness, takes the coordinated efforts of a full-service interprofessional care team (Hurwitz et al., 2004). When dealing with such challenging issues, it's critical that providers form a partnership with the patient and the family to achieve the best possible outcomes.

## The Art of Listening

Several months after David died, I found myself reflecting on what was missing from David's care. Why wasn't a professional health care provider available to listen to David's emotional and spiritual concerns throughout his cancer journey? Why did Joe and I have to plead with a reluctant physician to listen to our son's innermost fears so close to the end of his life? It needn't have been a specialist in psychiatry or pastoral care; rather, any clinician with whom the patient has a strong and trusting connection could have served in this role. This underscores why it's important that all members of the interdisciplinary team who treat patients like David be educated in palliative and end-of-life care issues. The meaning of a cancer diagnosis is not limited to one person's experience of the illness; cancer isn't only about death and dying. A cancer diagnosis has profound meaning not only for the patient but also for all involved in the patient's care.

Listening is probably the most important gift palliative care specialists can provide to patients and their families. Taking time to sit with the patient on a regular basis, without any interruptions, is crucial in fostering an atmosphere that's conducive to an exchange of thoughts and feelings. Providers should shut off all beepers, cell phones, and other devices, place a "Do Not Disturb" sign outside the patient's room, and close the patient's door (ELNEC-PPC, 2007). While they may be temporarily uncomfortable, moments of silence between a health care professional and a patient may be salutary, encouraging emotional reflection as well as exchanges of important information.

Clinical experts in the field of pediatric palliative care describe the importance of establishing trusting and respectful relationships over time, before engaging in candid conversations regarding advanced care planning (Wolfe et al., 2011). David was treated in several institutions in three states, so perhaps it isn't surprising that communications and relationships were sometimes fragmented. If David had a provider who had established a continuous relationship with him throughout the trajectory of his illness, he may have felt comfortable enough to open up and express his fears about illness and dying.

A trained palliative care nurse may have been the ideal provider to assess his needs from an integrative perspective. Ideally, the provider could have taken the time to get to know David and us, so that our ongoing needs could be anticipated. A palliative care nurse could coordinate complex care and assist with symptom management and psychosocial issues, allowing for more seamless transitions and, perhaps, initiating discussions about the goals of care well before David's condition

became critical. If we'd had the same coordinator of care from the point of diagnosis, then maybe David, his father, and I would have experienced different conversations toward the end of his life.

## Bereavement Follow-Up

Assisting families through the mourning process is an important part of comprehensive end-of-life care (Wolfe et al., 2011). While bereavement counselors may be available, few institutions allow the pediatric patient's health care team to provide follow-up bereavement care for family members after a patient has died (Hurwitz et al., 2004). However, researchers have shown that families experience a double loss: first, the loss of the child who has died, followed by the loss of their relationships with the professionals who cared for their child, often for months or years (Wolfe et al., 2011). Families often need to feel that the health care team hasn't abandoned them after their child has died. Providing follow-up phone calls to assess how the family is managing may be especially meaningful to parents (Davies, Limbo, & Jin, 2010) and may serve to identify families who are not coping well or who are at risk for physical, psychological, and social sequelae (Wolfe et al., 2011). Referrals to grief counselors and bereavement support groups may also be a welcome intervention for families (Davies et al., 2010).

## Implications for Health Care Professionals

Dissemination, implementation, and evaluation of educational programs in pediatric palliative care are advancing slowly. The need for pediatric palliative care education is vital and should be implemented in schools of medicine, nursing, social work, and counseling; such implementation would reduce the need for learning by trial and error (Contro, Larson, Scofield, Sourkes, & Cohen, 2004; Davies et al., 2008; Hilden et al., 2001; Schiffman et al., 2008; Shea, Grossman, Wallace, & Lange, 2010). Additionally, competency-based testing may be a method to evaluate program learning, as recommended by NHPCO (2001).

Despite the educational resources that do exist, most providers have yet to receive formal education related to the care of this patient population and their families (see Table 1). The lack of adequate preparation in palliative and end-of-life care for health care professionals has been confirmed by multiple research studies (Amery & Lapwood, 2004; Contro et al., 2004; Engler et al., 2004; Friebert & Huff, 2009). In fact, a qualitative study conducted by Docherty, Miles, and Brandon (2007) reported that most health care providers learned about palliative



care while on the job and felt fortunate if they had a mentor who was able to model high-quality care for them.

One barrier to the dissemination and implementation of this necessary education is the lack of funding to support such services. Gaining institutional support for integrating guidelines and standards into existing care facilities is no easy feat. However, the Center to Advance Palliative Care (2012) has developed materials to guide interested health care professionals in advocating for the implementation of hospital-based palliative care programs. Similarly, professional schools must also commit to the integration of palliative and end-of-life education into the curriculum, in order to bridge the gap in the formal education of future health care professionals. Without this foundational knowledge, future providers cannot fully comprehend how to alleviate suffering and promote better quality of life for children and families who live with a life-threatening condition. Again, garnering financial assistance to support faculty and curriculum development is crucial if implementation, dissemination, and evaluation of this educational effort are to succeed. Private, government, and community agencies may be potential avenues in securing resources.

### ***A New Role for Advanced Practice Registered Nurses***

The dynamic role of the advanced practice registered nurse (APRN) lends itself to advancing pediatric palliative care as a subspecialty (Morgan, 2009; Reed, 2010). The APRN's scope of practice includes improving quality of life by providing clinical expertise, pain and symptom management, and continuous integrative and coordinated care across health care settings. Developing and evaluating the role of the advanced practice nurse in pediatric palliative care may lead to improved patient outcomes and cost savings, as described by nurse researchers Brooten, Youngblut, Deatrick, Naylor, and York (2004).

However, at present there is sparse empirical evidence of the effectiveness of this pediatric subspecialty role. In our review of the literature, we found only one study (conducted in the United Kingdom) that describes the effect of advanced practice nurses in caring for children with progressive cancer (Vickers, Thompson, Collins, Childs, & Hain, 2007). Vickers and colleagues demonstrated that care provided by pediatric oncology nurse specialists supported children and families such that most of the children were allowed to be cared for, and to die, at home. This research adds to the validation of the nurse specialist role in pediatric palliative care; nurse specialists may provide a valuable interface between primary, secondary, and tertiary care services (Vickers et al., 2007).

Although empirical evidence of their effectiveness is lacking, programs coordinated by APRNs have been implemented within several of the leading children's hospitals in the United States. Goals for pediatric palliative care programs are to

- Ensure optimal symptom control and enhance quality of life
- Facilitate communication and coordination of a multidisciplinary health care team
- Support families in decision making
- Provide seamless transitions across settings
- Facilitate bereavement care when needed (Duncan et al., 2007; Himelstein, 2006; Mauricio, & Okhuysen-Cawley, 2010)

### ***Future Research***

Studies are needed in a variety of areas to determine whether the evidence demonstrates the effectiveness of pediatric palliative care. While a thorough discussion of the financial impact of pediatric palliative care programs and education is beyond the scope of this article, it should be noted that effectiveness is not only a question of outcomes but of costs. In clinical settings, providers may be reluctant to spend their time in lengthy conversations with patients and family members—time for which they may not be adequately reimbursed. Although disheartening, this is a valid concern. The financial impact of pediatric palliative and end-of-life care services needs further evaluation (Wolfe et al., 2011). Philanthropic contributions and grants may also supplement clinical programs and serve to inform the public of the purposes and goals of palliative and end-of-care for children.

In terms of research in palliative care education, such education programs must first be integrated and evaluated in professional schools. Both the content of education programs and the effectiveness of the pedagogical methods used must be evaluated, so that best practices can be identified and shared. Second, evidence-based best practices in education need to be disseminated, so that future health care professionals will be better prepared to care for children with life-threatening illness and their families. Third, research needs to be conducted to examine the effectiveness of the APRN in this subspecialty area, including how APRNs affect patient and family satisfaction as well as satisfaction among other pediatric team members.

### ***Conclusion***

Providing learning opportunities for health care professionals to participate in pediatric palliative and end-of-life education is vital in order to improve this type of specialty care. Developing an understanding of what

pediatric palliative care is, and what it is not, is important for all health professionals who care for children with life-threatening illness. As pediatric palliative care teams become more prevalent, models of excellence and the effectiveness of APRNs need to be documented and shared. Improved quality of life should be an expectation for these children and their families.

Pediatric palliative care should not be applied only in terminal cases; indeed, the full spectrum of palliative care services should be available to any child living with a life-threatening illness. Conversely, families should not feel burdened by fragmented care, inconsistent plans of care, or ineffective communications from their health care team. Live or die, palliative care is necessary for the child and the family's ability to carry on and manage through the journey.

**Editor's Note:** As a result of her experience caring for her son David over the course of his illness, Robin Kanarek, BSN, RN, has become an advocate for pediatric palliative and end-of-life care education. She actively speaks out on the psychosocial needs of parents and families who endure a diagnosis of childhood cancer, and her family has given essential support for the integration of pediatric palliative and end-of-life education in the nursing curriculum at Fairfield University. She believes health care providers must receive this education early to create change in the field of palliative care and hopes that, in the future, early exposure to palliative and end-of-life care education will stimulate students to pursue greater knowledge of this specialty area. Furthermore, she believes that students entering all health care fields should be better prepared for encounters with patients who have life-threatening illnesses and that such preparation involves practice in "having difficult conversations, being present, and listening actively," as these are instrumental, foundational communication skills.

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

### References

- American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care. (2000). Palliative care for children. *Pediatrics*, *106*, 351-357.
- Amery, J., & Lapwood, S. (2004). A study into the educational needs of children's hospice doctors: A descriptive quantitative and qualitative survey. *Palliative Medicine*, *18*, 727-733.
- Andreoni, V. M., Obrecht, J. A., & Bowden, V. R. (2007). Palliative care resources for the health professional. *MCN: The American Journal of Maternal/Child Nursing*, *32*, 305-310.
- Baile, W. F., Buckman, R., Lenzi, R., Glober, G., Beale, E. A., & Kudelka, A. P. (2000). SPIKES: A six-step protocol for delivering bad news: Application to the patient with cancer. *Oncologist*, *5*, 302-311.
- Beale, E. A., Baile, W. F., & Aaron, J. (2005). Silence is not golden: Communicating with children dying from cancer. *Journal of Clinical Oncology*, *23*, 3629-3636.
- Brooten, D., Youngblut, J. A., Deatrck, J., Naylor, M., & York, R. (2004). Patient problems, advanced practice nurse (APN) interventions, time and contacts among five patient groups. *Journal of Nursing Scholarship*, *35*(1), 73-79.
- Browning, D. M., & Solomon, M. Z. (2005). The initiative for pediatric palliative care: An interdisciplinary educational approach for healthcare professionals. *Journal of Pediatric Nursing*, *20*, 326-334.
- Center to Advance Palliative Care. (2012). *Building a hospital-based palliative care program*. Retrieved from [http://www.capc.org/building-a-hospital-based-palliative-care-program/case/support-from-capc/capc\\_publications/making-the-case.pdf](http://www.capc.org/building-a-hospital-based-palliative-care-program/case/support-from-capc/capc_publications/making-the-case.pdf)
- Contro, N., Larson, J., Scofield, S., Sourkes, B., & Cohen, H. J. (2004). Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics*, *114*, 1248-1252.
- Cooney, G. A. (2009, August 29). Helping patients cope with death (Letter to the editor). *New York Times*, p. A20.
- Davies, B., Brenner, P., Orloff, S., & Worden, W. (2002). Addressing spiritual needs in pediatric hospice and palliative care. *Journal of Palliative Care*, *18*, 59-66.
- Davies, B., Limbo, R., & Jin, J. (2010). Grief and bereavement in pediatric palliative care. In B. R. Ferrell & N. Coyle (Eds.), *Oxford textbook of palliative nursing* (3rd ed., pp. 1081-1097). New York, NY: Oxford University Press.
- Davies, B., Sehring, S. A., Partridge, J. C., Cooper, B. A., Hughes, A., Philp, J. C., & Kramer, R. F. (2008). Barriers to palliative care for children: Perceptions of pediatric health care providers. *Pediatrics*, *121*, 282-288. doi:10.1542/peds.2006-3153
- Docherty, S., Miles, M., & Brandon, D. (2007). Searching for "the dying point": Providers' experiences with palliative care in pediatric acute care. *Pediatric Nursing*, *33*, 335-341.
- Duncan, J., Spengler, E., & Wolfe, J. (2007). Providing pediatric palliative care: PACT in action. *MCN: The American Journal of Maternal/Child Nursing*, *32*, 279-287.
- End of Life Nursing Education Consortium. (2007). *Pediatric palliative care: Faculty guide*. Duarte, CA: American Association of Colleges of Nursing and City of Hope National Medical Center.
- Engler, A. J., Cusson, R. M., Brockett, R. T., Cannon-Heinrich, C., Goldberg, M. A., West, M. G., & Petow, W. (2004). Neonatal staff and advanced practice nurses' perceptions of bereave-

- ment/end-of-life care of families of critically ill and/or dying infants. *American Journal of Critical Care*, 13, 489-498.
- Feudtner, C., Haney, J., & Dimmers, M. (2003). Spiritual care needs of hospitalized children and their families: A national survey of pastoral of pastoral care providers' perceptions. *Pediatrics*, 111, e67-e72.
- Field, M. J., & Behrman, R. E. (Eds.). (2003). *When children die: Improving palliative and end of life care for children and their families*. Washington, DC: National Academies Press.
- Foster, T. L., Lafond, D. A., Reggio, C., & Hinds, P. S. (2010). Pediatric palliative care in childhood cancer nursing: From diagnosis to cure or end of life. *Seminars in Oncology Nursing*, 26, 205-221.
- Friebert, S., & Huff, S. (2009, February). NHPCO's pediatric standards: A key step in advancing care for America's children. *NewsLine*. Retrieved from [http://www.nhpc.org/files/public/quality/Peds-Standards\\_article\\_NL-0209.pdf](http://www.nhpc.org/files/public/quality/Peds-Standards_article_NL-0209.pdf)
- Garwick, A. W., Patterson, J., Bennett, F. C., & Blum, R. W. (1995). Breaking the news: How families first learn about their child's chronic condition. *Archives of Pediatrics & Adolescent Medicine*, 149, 991-997.
- Hartocollis, A. (2009, August 28). At the end, offering not a cure but comfort. *New York Times*, pp. A1, A16, A19.
- Hilden, J. M., Emanuel, E. J., Fairclough, D. L., Link, M. P., Foley, K. M., Clarridge, B. C., & Mayer, R. J. (2001). Attitudes and practices among pediatric oncologists regarding the end-of-life care: Results of the 1998 American Society of Clinical Oncology Survey. *Journal of Clinical Oncology*, 19, 205-212.
- Himmelstein, B. (2006). Palliative care for infants, children, adolescents, and their families. *Journal of Palliative Medicine*, 9, 163-181.
- Himmelstein, B. P., Hilden, J. M., Morstad Boldt, A., & Weissman, D. (2004). Pediatric palliative care. *New England Journal of Medicine*, 350, 1752-1762.
- Hinds, P. S. (1988). Adolescent hopefulness in illness and health. *Advances in Nursing Science*, 10, 79-88.
- Hurwitz, C., Duncan, J., & Wolfe, J. (2004). Caring for the child with cancer at the close of life. *Journal of the American Medical Association*, 292, 2141-2149.
- Kreicbergs, U., Valdimarsdottir, U., Onelov, E., Henter, J. I., & Steineck, G. (2004). Talking about death with children who have severe malignant disease. *New England Journal of Medicine*, 351, 1175-1186.
- Levetown, M. (2008). Communicating with children and families: From everyday interactions to skill in conveying distressing information. *Pediatrics*, 121, e1441-e1460. doi:10.1542/peds.2008-0565.
- Mack, J. W., Hilden, J. M., Watterson, J., Moore, C., Turner, B., Grier, H. E., & Wolfe, J. (2005). Parent and physician perspectives on quality of care at the end of life in children with cancer. *Journal of Clinical Oncology*, 23, 9155-9161.
- Mack, J. W., & Hinds, P. S. (2011). Practical aspects of communication. In J. Wolfe, P. Hinds, & B. Sourkes (Eds.), *Textbook of interdisciplinary pediatric palliative care* (pp. 179-189). Philadelphia, PA: Elsevier Saunders.
- Makoul, G. (2001). The SEGUE framework for teaching and assessing communication skills. *Patient Education & Counseling*, 45, 23-34.
- Masera, G., Chesler, M. A., Jankovic, M., Ablin, A. R., Ben Arush, M. W., Breatnach, F., & Spinetta, J. J. (1997). SIOOP Working Committee on psychosocial issues in pediatric oncology: Guidelines for communication of the diagnosis. *Medical Pediatric Oncology*, 28, 382-385.
- Mauricio, R. V., & Okhuysen-Cawley, R. (2010). The caring continuum: Role of the pediatric critical care advanced practice nurse in palliative care program development. *Critical Care Nursing Quarterly*, 33, 292-297.
- Meyer, E. C., Burns, J. P., Griffith, J. L., & Truog, R. D. (2002). Parental perspectives on end-of-life care in the pediatric intensive care unit. *Critical Care Medicine*, 30, 226-231.
- Morgan, D. (2009). Caring for dying children: Assessing the needs of the pediatric palliative care nurse. *Pediatric Nursing*, 35(2), 86-90.
- National Consensus Project for Quality Palliative Care. (2009). *Clinical practice guidelines for quality palliative care* (2nd ed.). Pittsburgh, PA: Author. Retrieved from <http://www.nationalconsensusproject.org>
- National Hospice and Palliative Care Organization. (2001). *A call for change: Recommendations to improve the care of children living with life-threatening conditions*. Alexandria, VA: Author. Retrieved from <http://www.nhpc.org/files/public/ChIPPSCallforChange.pdf>
- O'Shea, E. R., Wallace, M., Quinn Griffin, M., & Fitzpatrick, J. J. (2011). The effect of an educational program on pediatric nurses' perspectives toward providing spiritual care. *Journal of Pediatric Nursing*, 26, 34-43.
- Reed, S. (2010). A unitary-caring conceptual model for advanced practice nursing in palliative care. *Holistic Nursing Practice*, 24(1), 23.
- Sahler, O. J. Z., Frager, G., Levetown, M., Cohn, F. G., & Lipson, M. A. (2000). Medical education about end-of-life care in the pediatric setting: Principles, challenges, and opportunities. *Pediatrics*, 105, 575-584.
- Schiffman, J. D., Chamberlain, L. D., Palmer, L., Contro, N., Sourkes, B., & Sectish, T. C. (2008). Introduction of a pediatric palliative care curriculum for pediatric residents. *Journal of Palliative Medicine*, 11, 164-170.
- Shea, J., Grossman, S., Wallace, M., & Lange, J. (2010). Assessment of advanced practice palliative care nursing competencies in nurse practitioner students: Implications for the integration of ELNEC curricular modules. *Journal of Nursing Education*, 49, 183-189.
- Sumner, L. H. (2010). Pediatric hospice and palliative care. In B. R. Ferrell & N. Coyle (Eds.), *Oxford textbook of palliative nursing* (3rd ed., pp. 997-1017). New York, NY: Oxford University Press.

- Vickers, J., Thompson, A., Collins, G. S., Childs, M., & Hain, R. (2007). Place and provision of palliative care for children with progressive cancer: A study by the Paediatric Oncology Nurses' Forum/United Kingdom Children's Cancer Study Group Palliative Care Working Group. *Journal of Clinical Oncology*, 25, 4472-4476.
- Von Gunten, D. F., Ferris, F. D., & Emanuel, L. L. (2000). Ensuring competency in end-of-life care. *Journal of the American Medical Association*, 284, 3051-3057.
- Wolfe, J., Hinds, P. S., & Sourkes, B. M. (2011). *Textbook of interdisciplinary pediatric palliative care*. Philadelphia, PA: Elsevier.
- Yam, B. M., Rossiter, J. C., & Cheung, K. Y. (2001). Caring for dying infants: Experiences of neonatal intensive care nurses in Hong Kong. *Journal of Clinical Nursing*, 10, 651-659.

### Bios

**Eileen R. O'Shea, DNP, RN, CHPPN**, is an Assistant Professor in the School of Nursing at Fairfield University,

and a Clinical Instructor at Yale New Haven Children's Hospital. Dr. O'Shea is a pediatric ELNEC (End of Life Nursing Education Consortium) trainer and serves as a board member for the Connecticut Coalition to Improve End-of-Life Care. Her research interests include: pediatric palliative and end-of-life care, spiritual care, and holistic comfort for children living with life limiting conditions and their families.

**Robin Bennett Kanarek, BSN, RN**, is President of the Kanarek Family Foundation, established in 2006 to honor the memory of her son, David. She also serves as the Chair of Fairfield University's Nursing Advisory Board in Fairfield, CT. The Foundation has provided nursing grants to improve pediatric and adolescent palliative care at Fairfield University School of Nursing (Fairfield, CT), as well as, Memorial Sloan-Kettering Cancer Center (New York, NY).