Pediatric Palliative Care

Michelle R. Brown and Barbara Sourkes

The goal is to add life to the child's years, not simply years to the child's life.
(American Academy of Pediatrics [AAP], 2000)
Food, toys and love are what we need to live!
6-year-old child (Sourkes, 1995, p. 112)

Introduction

Pediatric palliative care is a new interdisciplinary frontier in the comprehensive care of children living with serious medical conditions. Over the last two decades, an integrated vision toward their optimal care has begun to emerge (Association for Children with Life-threatening and Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health, 2003; Institute of Medicine, 2003). Broadly defined:

> Palliative care for children and young people with [complex chronic], life-limiting or life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life and death. It embraces physical, emotional, social and spiritual elements, and focuses on enhancement of quality of life for the child/young person, support for the family, [decision-making and the establishment of goals of care for the child]. It includes the management of distressing symptoms, provision for respite, and care through death and bereavement. [Palliative care may extend over many years.] (Together for Short Lives, 2018, p. 9)

"Life-threatening" includes illnesses for which cure is possible, although the threat of death remains. Such an illness may convert into a life-limiting condition when curative options no longer exist. "Life-limiting conditions" include those for which there is no reasonable chance of cure from the outset; even if children survive years and decades, they will not live out a normal life expectancy. The inclusion of "complex chronic" conditions is recent and attests to the fragility of children living with incurable diseases even when the diagnosis does not portend premature death. As is evident, end-of-life and hospice care are not synonymous with palliative care; rather, they are components of this very broad spectrum of care.

Traditionally, palliative care was only initiated late in the course of an illness, once all curative options were exhausted. Disease-directed therapy and palliative care were considered mutually exclusive. Today, the emerging model is of *concurrent care*, whereby disease-directed therapy (curative/life-prolonging) and palliative care (symptom management, decision-making, quality-of-life considerations) coexist throughout the illness trajectory, although their emphasis may shift at different stages of the illness.

M. R. Brown (✉)
Lucile Packard Children's Hospital Stanford,
Palo Alto, CA, USA

Department of Psychiatry, Stanford University School of Medicine, Stanford, CA, USA
e-mail: brownmi@stanford.edu

B. Sourkes
Lucile Packard Children's Hospital Stanford,
Palo Alto, CA, USA

Department of Pediatrics, Stanford University School of Medicine, Stanford, CA, USA

B. D. Carter, K. A. Kullgren (eds.), *Clinical Handbook of Psychological Consultation in Pediatric Medical Settings*, Issues in Clinical Child Psychology, https://doi.org/10.1007/978-3-030-35598-2_36

Pediatric palliative care encompasses a broad range of ages and disease-related conditions. With over half of all childhood deaths occurring under 1 year of age, most often related to congenital disorders and chromosomal abnormalities potentially detectable during the perinatal period (Heron, 2018), palliative care may be initiated even before a child's birth. The spectrum of disease-related conditions across the age span can be conceptualized to fall within one of four categories (Association for Children with Life-threatening and Terminal Conditions and their Families, National Council for Hospice and Specialist Palliative Care Services, Scottish Partnership Agency for Palliative and Cancer Care, 2001):

1. Life-threatening conditions for which curative treatment may be feasible but can fail (e.g., cancer).
2. Conditions in which premature death is anticipated but intensive treatment may prolong life and improve quality of life (e.g., cystic fibrosis).
3. Progressive diseases for which treatment is exclusively palliative and may extend over years (e.g., Duchenne muscular dystrophy).
4. Irreversible but nonprogressive conditions causing severe disability that lead to susceptibility to health complications and likelihood of premature death (e.g., severe cerebral palsy).

Impact of Pediatric Palliative Care

While the science of pediatric palliative care is emerging, the majority of the evidence base consists of retrospective cohort studies and qualitative or descriptive case studies, rather than randomized controlled trials. Systematic review is complicated by the fact that the practice of pediatric palliative care is broad, where a comprehensive set of services are provided to a wide age range of children across a number of disease groups at various points along the illness trajectory, while the evidence regarding impact is often narrowly focused on a specific outcome in a particular patient population. Yet, among the existent literature, integration of pediatric palliative care services appears to improve outcomes, including improved pain and symptom management (Wolfe et al., 2008) and quality of life (Friedrichsdorf et al., 2015), reduced length of stay in the pediatric intensive care unit and emergency department visits (Ananth, Melvin, Feudtner, Wolfe, & Berry, 2015), fewer invasive interventions and deaths in the ICU (Keele, Keenan, Sheetz, & Bratton, 2013), and improved end-of-life communications with children and families (Kassam, Skiadaresis, Alexander, & Wolfe, 2015).

The Team in Pediatric Palliative Care

Pediatric palliative care requires an interdisciplinary team to deliver optimal care. Whether the team is a formally defined set of professionals, or a group of individuals who come together as needed to design and provide palliative care interventions, integration of care is crucial. While each member of the team brings a unique specialization and perspective, a certain overlap in knowledge and skills is also evident. An overarching challenge for an interdisciplinary team is to promote a unified approach toward care, while respecting and building on each profession's contribution (Friebert, Chrastek, & Brown, 2011; Papadatou, Bluebond-Langner, & Goldman, 2011; Sourkes et al., 2005). Virtually all pediatric palliative care teams function as *consultants* to the primary team; that is, they do not take over primary care of the child. Continuity of care across treatment setting is emphasized and, when possible, palliative care teams meet with children and families on both an inpatient and outpatient basis, in addition to coordinating care with community providers.

Teams vary in composition depending on many factors, including the readiness of the institution to embrace palliative care, the availability of expertise in different disciplines, and financial support. Most programs function with a core team (or even just one "core" individual)—often a physician and/or nurse—who partners with the primary team and ancillary services who are already involved in the patient's care. Psychologists less often have time formally allocated to pediatric palliative care teams (Feudtner et al., 2013). Rather, psychologists who care for patients with chronic, complex, life-threatening conditions through either an inpatient consultation-liaison service or an outpatient medical subspecialty may collaborate with the palliative care team to formulate a comprehensive, interdisciplinary treatment plan. Among the care providers, open communication and flexible boundaries are key in delineating roles, which will vary by case and throughout a patient's course of treatment.

Pediatric Palliative Care Consultation: Children and Families

Reasons for referral of a child and family to the pediatric palliative care team fall into the following overlapping categories.

Symptom Management

Children who live with a complex chronic or life-threatening illness face extraordinary physical and psychological challenges. Whether children are receiving disease-oriented or palliative treatment—or both concurrently—enhancing their comfort and minimizing their distress is an ongoing challenge. While many physical symptoms are a predictable manifestation of an underlying disease or disorder, the intensity and frequency of their occurrence can be highly variable. Psychological symptoms are often not as predictable and, as a result, may take longer to identify and address. Common symptoms include pain, nausea and vomiting, fatigue, weakness, depression, and anxiety. To varying degrees, these symptoms can comprise both physical and psychological components; social and cultural or religious factors may all impact how children experience and interpret symptoms.

While it is important not to overemphasize psychopathology in the medically ill child, there is also a risk failing to recognize or minimizing important symptoms. Although sadness and anxiety are typical and expected reactions to prolonged illness and treatment, under sustained stress, such responses may progress to clinical disorders that necessitate psychotherapy and/or psychotropic medication. This is especially true in the child with preexistent vulnerabilities, or when there is a prior psychiatric history in the child or a family member. Differential diagnosis may be difficult since normal emotions of sadness and grief overlap with the symptoms of a clinical depression (e.g., crying, changes in appetite, sleep difficulties, and decreased concentration). Somatic symptoms of depression and anxiety also overlap considerably with the physical effects of illness and its treatment. The presence of anhedonia, feelings of worthlessness, or self-blame may help to differentiate psychological symptoms from the illness process and/or treatment. As physical effects of illness and treatment significantly impact mood and anxiety (e.g., sleep deprivation, pain), it is also critical to assess and treat such symptoms (Muriel, Case, & Sourkes, 2011; Sourkes et al., 2005).

Decision-Making and Establishing Goals of Care

Uncertainty and hope coexist throughout the trajectory of a child's life-threatening condition. Palliative care offers children and families an opportunity to consider goals for their care in light of what is known about the prognosis, treatment options, and available means for enhancing their quality of life (Kasl-Godley, King, & Quill, 2014). Direct and compassionate communication, whereby families feel respected and supported, facilitates their partnership with the team in developing an overarching plan. These discussions are especially critical when curative or life-prolonging treatment options are diminished or no longer exist. Asking about what the child and family are hoping for is the first step in defining goals. Whereas an initial response may speak to the hope for their child's survival, query about *additional* hopes often reveals families' values and their concerns about quality of life. For example, some families define hope as exhausting all possible treatment options. They may elect to proceed with highly experimental therapies that necessitate hospitalization and procedures, even with little likelihood of long-term survival. Other families may choose to focus on comfort and minimizing suffering as a priority, with the hope that the child can spend as much time as possible outside of the hospital. These discussions should be revisited as changes occur in the child's condition or new clinical information becomes available—or simply because hope is a dynamic entity and thus goals can shift over time.

The establishment of goals of care guides how the medical team presents treatment options and how families choose a pathway for their child. Historically, the paternalistic culture of western medicine meant that treatments were decided by the physician with little input from the patient and family. More recently, with a focus on autonomy, families are often asked to choose among treatment options that are offered. Families with no medical training or overall context can be overwhelmed by the responsibility of making such critical decisions. Palliative care providers are instrumental in helping families examine the benefits (the likelihood of success) and burdens inherent in the treatment. Burdens include not only pain and suffering per se, but the broader impact on children and their families' quality of life. The palliative care team can also guide the primary providers in *recommending* the option that seems most aligned with medical reality and with the values of the family. Any recommendation, of course, is counterbalanced by the reassurance to families that the team will continue to care for the child regardless of the option they choose. Expected "waypoints" should also be identified to prepare the family for developments or events that lend themselves to reevaluation of the appropriateness of the treatment plan (Macauley, 2018).

There are instances when disagreements arise between the medical team and families around what is "best" for the child. In some instances, the family wants to continue or pursue additional disease-directed treatment regimens, when the medical team no longer sees their value; the converse can also occur. An important role of the palliative care team can be to meet separately with the team and the family, listen carefully to their viewpoints, and then facilitate discussions between them to arrive at a compromise, if possible. These interventions can be critical in preventing the escalation of polarization and conflict.

In most instances, parents are tasked with making treatment decisions that are in the child's best interests. However, to varying degrees, children and adolescents may be involved in such discussions. Although very young children cannot participate meaningfully in medical decision-making, as children reach school age, many understand the realities and implications of their condition. Some children and adolescents may be hesitant to express their thoughts about treatment options, particularly when their wishes or goals differ from those of the parents and medical providers. At these critical junctures, the palliative care psychologist can be an important liaison, by bringing the child's voice (either by encouraging the child to speak directly or by report) into the discussion toward a common goal.

Advance Care Planning

Advance care planning enables patients to express their goals and values for future eventualities in case they lose their decision-making capacity at some point during the illness. Specific treatment that they wish to receive or decline (including intubation and cardiopulmonary resuscitation) can be documented in a legally binding advance care directive. Much of the literature on pediatric advance care planning has focused on the parents, since they have legal decision-making authority for their children. Parents are encouraged to clarify and document their wishes for their child proactively, so that they are not forced to make critical decisions in the extreme stress of a life-threatening crisis. Although preferences may change in the moment, research has shown that parents typically adhere to previously expressed decisions when such situations present themselves (Hammes, Klevan, Kempf, & Williams, 2005).

There is increasing belief that children and adolescents should also have a role in decision-making for their end-of-life care (American Academy of Pediatrics, 2000; Hinds et al., 2005) and many adolescents express the desire to be included (Lyon, McCabe, Patel, & D'Angelo, 2004). Research has shown that, as a result of being involved in advance care planning discussions, adolescents were better informed about end-of-life decisions and were more likely to limit disease-oriented treatments (Lyon, Jacobs, Briggs, Cheng, & Wang, 2013). Whereas advance care planning enables providers and families to understand and honor the adolescents' wishes, providers (Davies et al., 2008; Feudtner, 2007) and parents (Steele & Davies, 2006) report difficulty initiating such discussions. Advance care planning tools such as Voicing My CHOiCES (Zadeh, Pao, & Wiener, 2015) and My Wishes (Aging with Dignity, 2018) may be helpful in fostering such conversations using a developmentally appropriate approach and language. Of course, even in the absence of a written document, the process of communication may foster collaborative decision-making and articulation of a clear treatment plan.

Planning for Care at the End of Life

Palliative care providers can assist families in anticipating and preparing for the time when death is certain and imminent and care shifts toward the optimization of the child's comfort. Care can be provided in a variety of settings. The majority of children (~56%) die in the hospital (of these, more than 85% in the intensive care unit) (Carroll, Wright, & Frankel, 2011), the home (with or without home hospice support), and, infrequently, in freestanding hospices for children or long-term care facilities. When there is the possibility to plan for the setting, some families choose to stay in (or return to) the hospital for the child's death. Reasons include strong relationships with their hospital "family," inadequate resources at home, or cultural or religious beliefs that limit the use of hospice care. Other families wish for their children to be cared for away from the confines of the hospital, opting for hospice services at home. While hospice can refer to a physical place, more commonly, it refers to a health-care system providing palliative care in a home environment. It is crucial that the staff respect the family's choice and reassure them that they can change course at any time. Recent studies have shown that families' opportunity to plan for the child's death in their *preferred* location may be a more important variable than the actual location of death; it was associated with parental perceptions of high-quality end-of-life care (Dussel et al., 2009).

Psychological Guidance, Assessment, and Treatment

As the field of pediatric palliative care develops, there is a window of opportunity to define the parameters of optimal psychological care for these children. Ideally, the psychological status of each child who is referred to palliative care should be evaluated in the same way as medical and nursing assessments are performed. The specific contribution of the psychologist (and other mental health professionals) include evaluation of the child's psychological status, diagnosis of psychological/psychiatric symptoms and disturbance, psychotherapy and recommendations for psychotropic medication, and guidance for the family and team.

Within the framework of psychotherapy—through words, drawings, and play—children may confront the exigencies of living with life-threatening illness, express the ebb and flow of anticipatory grief and hope, and, at times, find their voice in the decision-making process (Muriel et al., 2011; Sourkes et al., 2005). While the evidence base for psychotherapeutic approaches with children and adolescents in palliative care is not yet developed, many best practices can be extrapolated from the broader literature in child clinical (Weisz & Kazdin, 2017) and pediatric psychology (Carter, 2014). Cognitive-behavioral therapy, motivational interviewing, and acceptance and commitment therapy all provide interventions relevant to the concerns that present in children with life-threatening disease. Self-help techniques such as relaxation, guided imagery, and hypnosis may be integrated into the process. The psychotherapeutic relationship itself can be a profound intervention in managing children's distress, as it affords a space wherein emotions can be expressed freely, without fear of others' reactions. On its own or in combination with the child's individual psychotherapy, family therapy can open lines of communication and play a pivotal role in sustaining and strengthening coping resources for each member. Healthy siblings, who have lived through the illness experience with the same intensity as the child and parents, should be included in the care.

There are two caveats to bear in mind with regard to psychological intervention in pediatric palliative care. First is that the availability of psychological consultation is often limited. Under these circumstances, other team members can provide thoughtful emotional support for the child in a carefully planned manner, ideally in consultation with a mental health professional. While it is true that psychological treatment is not universally necessary, the ability to identify "high-risk" children and intervene in a timely fashion is extremely important. A second caveat is that many children in pediatric palliative care have diagnoses with cognitive as well as physical manifestations. The spectrum includes children with mild/moderate limitations to those with severe global developmental deficits and minimal awareness of the world around them. In addition are children who, although cognitively unaffected, may not be able to communicate effectively during certain phases of the illness. Thus, traditional modes of assessment and intervention may not be appropriate at all, or, at the least, must be adapted.

Bereavement Follow-Up

Bereavement follow-up by the professional team is an intrinsic component of comprehensive pediatric palliative care. Families often express the sense of a double loss: first and foremost is the loss of their child, and second, compounding their grief, they mourn the loss of their "professional family"—the treatment team whom they have known and trusted, often over years (Contro, Larson, Scofield, Sourkes, & Cohen, 2002). Contact from a team member after the child's death not only assuages the family's sense of abandonment, but it can also serve a crucial preventive role in identifying families at heightened risk for serious psychological, social, emotional, and physical sequelae. The palliative care team, in conjunction with community providers, may assess the needs of bereaved families and either provide the necessary follow-up or advocate for and engage appropriate resources for them (Contro, Kreicbergs, Reichard, & Sourkes, 2011; Contro & Sourkes, 2012).

Pediatric Palliative Care Consultation: Trainees and Staff

Consultation and support for staff and trainees is also a vital role for the palliative care team. These interventions may take the form of individual (confidential) meetings, team debriefings, or educational sessions. In addition to the request to discuss palliative care management of a specific child, themes across all these formats include the impact of working with seriously ill children and their families on one's personal and professional life, distress when one's own values are not congruent with those of a family or one's team, conflict within a team or between the team and family, the impact of a child's death and the toll of cumulative loss, and preserving resilience over the "long haul."

Crosscutting Considerations

Culture

From its inception, the field of palliative care has been attentive to culturally determined aspects of care, beginning at the most basic level with the impact of language barriers, including nonverbal communication (Strada, 2018). How families communicate with their child about diagnosis and prognosis, from an open approach to one of limiting information with the goal of protection, may derive from their cultural background more than from their "psychology." The locus of decision-making may depend on how "collectively" family is defined—and determine whether the parents defer to an authority figure in the family or to a larger group of extended family. Gender differences, particularly the role of women in the family, can be significant. Cultural meanings of illness and death can affect the experience and tolerance of pain (Wiener, McConnell, Latella, & Ludi, 2013), openness to discuss treatment preferences at the end of life, and attitudes toward hospice care (Macauley, 2018; Strada, 2018).

Given the many ways that cultural differences can influence children's and families' experience of life-threatening illness, asking about their background is a critical part of an overall assessment. Medical interpreters play an invaluable role in interpreting not only words, but also styles of communication and culture. Culturally competent palliative care requires patience and respect from the team in creating a therapeutic alliance.

Spirituality/Religion

Many families identify spirituality and religion as important in the face of illness and death: from making sense of and ascribing meaning to the experience to finding and defining hope, to providing guidance in decision-making, to giving emotional sustenance. In one study, 73% of parents reported that spirituality or religion was what helped them the most during the last stages of their child's illness (Robinson, Thiel, Backus, & Meyer, 2006). Yet many health-care professionals lack training (and comfort) in discussing these issues with families. Newly published guidelines have recognized the need to focus on spiritual care as a central domain in palliative care (National Consensus Project for Quality Palliative Care, 2018).

Ethics

Ethical issues in palliative care arise when the personal, cultural, and institutional values involved in decision-making conflict, whether among family members, between patient and family, patient/family and provider, or among professionals. Determining "the right thing to do" in emotionally laden life and death situations involving children is a huge challenge, for families and for medical teams alike. Consultation with an institution's ethics team can help to delineate the concerns and offer recommendations based upon identified ethical principles and precedent. Following are the key ethical dilemmas that arise most commonly in pediatric palliative care (Macauley, 2018):

- Requests for nondisclosure. In the desire to protect their child from overwhelming emotion, parents may ask the medical team not to share information related to their illness. This request often causes significant distress for medical teams who value open communication and access to information.
- Nonbeneficial care. Significant advances in medicine have contributed to the false assumption that every sick child can be cured. When are interventions "medically futile"?
- Refusal of medical treatment. While the standard for pediatric decision-making is consent of the parents and assent of the child, there are times when either the family rejects the "best" treatment option for their child or the child or adolescent's goals for treatment differ from those of the parents and medical team.
- Withholding or withdrawing life-sustaining medical intervention. Who makes that decision for the child? What are the criteria? How is quality of life defined for this child?

Barriers to Optimal Pediatric Palliative Care

There are many medical, psychosocial cultural, and financial barriers to the ideal delivery of comprehensive pediatric palliative care. Perhaps the greatest barrier is the still prevalent view that curative and palliative care are mutually exclusive. As a result, in the face of prognostic uncertainty, both medical teams and families may perceive palliative treatment as "giving up." Physicians may wait to initiate palliative care until they are absolutely certain that curative options no longer exist and that death is inevitable. In so doing, the provision of valuable services may be delayed, and opportunities to support quality of life for the child throughout the course of treatment, as well for the family, may be missed. One of the foremost goals of the field is to initiate palliative care for children proactively, early in the illness trajectory. An uncertain prognosis should be a signal to initiate, rather than to delay, palliative care (Sourkes et al., 2005).

Misconceptions and fear around the use of opioids for pain and symptom management are another barrier (Collins, Berde, & Frost, 2011). Many professionals are not comfortable in prescribing the appropriate escalating dosages necessary for optimal symptom management, often because they have not been educated in the principles of their administration. Both families and professionals may harbor fears about whether these drugs will cause addiction or immediately hasten the death of a child. These factors may lead to the imposition of limits on the very medications that would otherwise contribute to the child's comfort and potentially enhance quality of life over an extended period—not just in the last phases of the illness.

At the hospital level, staffing issues often serve as barriers to optimal palliative care. Physicians typically rotate off-service on a weekly or biweekly basis and primary nursing care is often not available. These frequent changes in the treatment team may contribute to miscommunication and confusion around the child's treatment plan. An incoming team may lack clarity about the rationale for a family's goals or care and/or may disagree with a previous team's direction or decisions. Varying levels of experience with palliative care generally, and understanding of the model of concurrent care specifically, may also cause confusion among providers.

Community barriers include the paucity of hospice and other health-care professionals familiar with pediatric symptom management. Children and their families typically become intensely dependent on the specialists in their tertiary care center for all aspects of their care. As a result, community professionals, including their primary pediatrician, often miss opportunities to gain expertise in pediatric palliative care. There continues to be a concerted effort to educate community practitioners both through didactic training and through discussions to address their concerns about working with seriously ill and dying children and their families.

Reimbursement issues are another major hindrance in developing comprehensive palliative care services (Harris, 2004). For many years, children with life-threatening illnesses were not eligible for palliative services while receiving curative or life-prolonging care. More recent legislation such as the Concurrent Care for Children Requirement of the Affordable Care Act (2010) has enabled children who are eligible for hospice to receive all other services related to the treatment of their condition, including those deemed life-prolonging such as blood transfusions and palliative chemotherapy.

Pediatric Palliative Care Consultation: Case Studies

Sarah was a 17-year-old girl diagnosed with a brain tumor at the age of 15. She had undergone three surgeries together with chemotherapy and radiation. She had one remission (disease-free period) of 9 months' duration. Following relapse and subsequent hospitalization, the palliative care team was consulted to discuss goals of care with Sarah and her family. In a series of care conferences, in which the palliative care team was present, the oncology team explained that any remaining treatment options were of uncertain benefit and could cause serious complications, or even shorten her life. The team presented "comfort only" measures as an equally acceptable option. Over the next days, Sarah and her parents weighed the benefits and burdens of various interventions, in discussions among themselves and with members of the palliative care team. Ultimately, they elected to pursue the route of palliative care at home, where Sarah received excellent symptom management from a community hospice. She died peacefully 4 months later.

Sarah's story illustrates the traditional model in which disease-directed care transitioned to palliative measures once cure was no longer an attainable goal. The illness course had a somewhat predictable timeframe and symptom management was relatively straightforward, allowing her to preserve good quality of life until her death.

Role of psychologist: Sarah was followed in psychotherapy beginning 1 year after her diagnosis. (The referral to the palliative care psychologist actually served as a point of entry for the entire palliative care team.) Major themes of discussion included awareness of her poor prognosis and how she would know when she had had "enough," concern for her parents and her 12-year-old brother and the pain of witnessing their suffering, deciding which meetings with the medical team she wanted to attend—and which she just wanted her parents to "report back" on, and the "what if's," in particular her wish that her parents make any decisions for her if she were not no longer competent. Through her intensifying anticipatory grief, Sarah articulated her emerging goals of care: if her time were limited, she wanted to be home with her family. The psychologist also met several times with Sarah's brother (as well as maintaining contact with his school counselor) to ensure that his concerns were addressed. After Sarah's death, the psychologist provided follow-up for her brother and referred the parents to a couple's therapist in the community who was experienced in bereavement.

Carlos was an infant in whom heart failure and neurologic anomalies had been identified prenatally by ultrasound. However, the diagnosis of a complex genetic syndrome was not confirmed until he was a month old. Because neither the diagnosis nor the prognosis were yet certain, parents expressed a desire to pursue all interventions that would give him the best chance for long-term survival. The neonatology and cardiology services consulted the palliative care team at this juncture. In his first week of life, Carlos was evaluated for potential listing for a heart transplant. He then underwent placement of a biventricular assist device (BiVAD)—an artificial heart—to support his heart function while he awaited a donor organ. While he initially responded favorably to the BiVAD, over the subsequent weeks, he developed serious complications including excessive blood clotting, a septic event causing pulmonary hemorrhage, followed by a stroke resulting in significant neurological injury. Given the parents' concerns about both his immediate suffering and longer-term quality of life, they requested that the BiVAD be discontinued. At the age of 8 weeks, he was disconnected from the BiVAD, extubated, and died in his parents' arms.

Carlos's care exemplified the way which intensive medical intervention and palliative care can be provided concurrently, with each predominating at different points along his treatment course. Carlos's parents faced several critical junctures of decision-making after uncertain prenatal ultrasounds: to initiate heart transplant evaluation and place onto a BiVAD, to continue with intensive care following a number of complications, and then to remove all intensive care measures. At each decision point, his parents carefully reexamined their goals of care, balancing their hopes to prolong his life with their desire to minimize his suffering.

Role of psychologist: The palliative psychologist initially met the parents during transplant evaluation and remained available throughout Carolos's life. The sessions were a forum for the parents to articulate their thinking, both individually and as a couple, and to provide guidance about explaining Carlos' illness and death to their 4-year-old son. When the parents' brought up their fear for any future pregnancies, the psychologist introduced them to a genetic counselor who would be available to meet with them in the future. The parents welcomed a referral to an organization focused on bereavement after neonatal death and maintained occasional telephone contact with the psychologist. The hospital team requested a debriefing after Carlos's death; they had become very attached to this family and wanted to understand better the concurrence of intensive intervention coupled with palliative care and how the family had negotiated this duality.

Future Directions

The field of pediatric palliative care offers unique opportunities for pediatric psychologists to participate in enhancing the quality of life of our most vulnerable children and families. Although psychological services have been integrated into medical settings, they remain on the periphery in pediatric palliative care (Feudtner et al., 2013), limiting opportunities for clinical exposure and training. A number of resources exist that provide education in palliative care more broadly including the *Clinical Practice Guidelines for Quality Palliative Care, Fourth Edition* (National Consensus Project for Quality Palliative Care, 2018), and programs through Education in Palliative and End-of Life Care (EPEC; http://www.epec.net) and the End-of-Life Nursing Education Consortium (ELNEC; http://www.aacn.nche.edu/elnec). Pediatric specific materials are available through the National Hospice and Palliative Care Organization (NHPCO; http://www.nhpco.org/palliative-care-resources-series).

Formal training programs or certification options are not yet available for psychologists. Specific knowledge and skills necessary for psychologists to engage in effective palliative care recently have been proposed (Kasl-Godley et al., 2014; Strada, 2018). Future development of practice guidelines and standardized training curriculum will promote increased integration of psychology into pediatric palliative care as the field continues to evolve.

References

Aging with Dignity. (2018). My Wishes.

American Academy of Pediatrics. (2000). Palliative care for children. *Pediatrics, 106*(2 Pt 1), 351–357.

Ananth, P., Melvin, P., Feudtner, C., Wolfe, J., & Berry, J. G. (2015). Hospital use in the last year of life for children with life-threatening complex chronic conditions. *Pediatrics, 136*(5), 938–946. https://doi.org/10.1542/peds.2015-0260

Association for Children with Life-threatening and Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health. (2003). *A guide to the development of children's palliative care services*. Bristol.

Association for Children with Life-threatening and Terminal Conditions and their Families, National Council for Hospice and Specialist Palliative Care Services, Scottish Partnership Agency for Palliative and Cancer Care. (2001). *Palliative care for young people ages 13–24*. London.

Carroll, J. M., Wright, J., L., & Frankel, L. R. (2011). Settings of care. In J. Wolfe, P. S. Hinds, & B. M. Sourkes (Eds.), *Textbook of interdisciplinary pediatric palliative care* (pp. 64–73). Philadelphia: Elsevier/Saunders.

Carter, B. (2014). Introduction to the CPPP special issue on evidence-based interventions in pediatric psychology. *Clinical Practice in Pediatric Psychology, 2*(3), 207–211.

Collins, J. J., Berde, C. B., & Frost, J. A. (2011). Pain assessment and management. In J. Wolfe, P. S. Hinds, & B. M. Sourkes (Eds.), *Textbook of interdisciplinary pediatric palliative care* (pp. 284–299). Philadelphia: Elsevier/Saunders.

Contro, N., Kreicbergs, U., Reichard, W., & Sourkes, B. M. (2011). Anticipatory grief and bereavement. In J. Wolfe, P. S. Hinds, & B. M. Sourkes (Eds.), *Textbook of interdisciplinary pediatric palliative care* (pp. 41–54). Philadelphia: Elsevier/Saunders.

Contro, N., Larson, J., Scofield, S., Sourkes, B., & Cohen, H. (2002). Family perspectives on the quality of pediatric palliative care. *Archives of Pediatrics & Adolescent Medicine, 156*(1), 14–19.

Contro, N., & Sourkes, B. M. (2012). Opportunities for quality improvement in bereavement care at a children's hospital: Assessment of interdisciplinary staff perspectives. *Journal of Palliative Care, 28*(1), 28–35.

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*(2), 282–288. https://doi.org/10.1542/peds.2006-3153

Dussel, V., Kreicbergs, U., Hilden, J. M., Watterson, J., Moore, C., Turner, B. G., … Wolfe, J. (2009). Looking beyond where children die: Determinants and effects of planning a child's location of death. *Journal of Pain and Symptom Management, 37*(1), 33–43. https://doi.org/10.1016/j.jpainsymman.2007.12.017

Feudtner, C. (2007). Collaborative communication in pediatric palliative care: A foundation for problem-solving and decision-making. *Pediatric Clinics of North America, 54*(5), 583–607,. ix. https://doi.org/10.1016/j.pcl.2007.07.008

Feudtner, C., Womer, J., Augustin, R., Remke, S., Wolfe, J., Friebert, S., & Weissman, D. (2013). Pediatric palliative care programs in children's hospitals: A cross-sectional national survey. *Pediatrics, 132*(6), 1063–1070. https://doi.org/10.1542/peds.2013-1286

Friebert, S., Chrastek, J., & Brown, M. R. (2011). Team relationships. In J. Wolfe, P. S. Hinds, & B. M. Sourkes (Eds.), *Textbook of interdisciplinary pediatric palliative care* (pp. 148–158). Philadelphia: Elsevier/Saunders.

Friedrichsdorf, S. J., Postier, A., Dreyfus, J., Osenga, K., Sencer, S., & Wolfe, J. (2015). Improved quality of life at end of life related to home-based palliative care in children with cancer. *Journal of Palliative Medicine, 18*(2), 143–150. https://doi.org/10.1089/jpm.2014.0285

Hammes, B. J., Klevan, J., Kempf, M., & Williams, M. S. (2005). Pediatric advance care planning. *Journal of Palliative Medicine, 8*(4), 766–773. https://doi.org/10.1089/jpm.2005.8.766

Harris, M. B. (2004). Palliative care in children with cancer: Which child and when? *Journal of the National Cancer Institute. Monographs, 2004*(32), 144–149. https://doi.org/10.1093/jncimonographs/lgh007

Heron, M. (2018). *Deaths: Leading causes for 2016. National vital statistics reports*, *67*(6). Hyattsville, MD: National Center for Health Statistics.

Hinds, P. S., Drew, D., Oakes, L. L., Fouladi, M., Spunt, S. L., Church, C., & Furman, W. L. (2005). End-of-life care preferences of pediatric patients with cancer. *Journal of Clinical Oncology, 23*(36), 9146–9154. https://doi.org/10.1200/JCO.2005.10.538

Institute of Medicine. (2003). *When children die: Improving palliative and end-of-life care for children and their families*. Washington, DC: The National Academies Press. https://doi.org/10.17226/10390

Kasl-Godley, J. E., King, D. A., & Quill, T. E. (2014). Opportunities for psychologists in palliative care: Working with patients and families across the disease continuum. *The American Psychologist, 69*(4), 364–376. https://doi.org/10.1037/a0036735

Kassam, A., Skiadaresis, J., Alexander, S., & Wolfe, J. (2015). Differences in end-of-life communication for children with advanced cancer who were referred to a palliative care team. *Pediatric Blood & Cancer, 62*(8), 1409–1413. https://doi.org/10.1002/pbc.25530

Keele, L., Keenan, H. T., Sheetz, J., & Bratton, S. L. (2013). Differences in characteristics of dying children who receive and do not receive palliative care. *Pediatrics, 132*(1), 72–78. https://doi.org/10.1542/peds.2013-0470

Lyon, M. E., Jacobs, S., Briggs, L., Cheng, Y. I., & Wang, J. (2013). Family-centered advance care planning for teens with cancer. *JAMA Pediatrics, 167*(5), 460–467. https://doi.org/10.1001/jamapediatrics.2013.943

Lyon, M. E., McCabe, M. A., Patel, K. M., & D'Angelo, L. J. (2004). What do adolescents want? An exploratory study regarding end-of-life decision-making. *Journal of Adolescent Health, 35*(6), 529.e521–529.e526. https://doi.org/10.1016/j.jadohealth.2004.02.009

Macauley, R. C. (2018). *Ethics in palliative care: A complete guide*. New York, NY: Oxford University Press.

Muriel, A. C., Case, C., & Sourkes, B. M. (2011). Children's voices: The experiences of patients and their siblings. In J. Wolfe, P. S. Hinds, & B. M. Sourkes (Eds.), *Textbook of interdisciplinary pediatric palliative care* (pp. 18–29). Philadelphia: Elsevier/Saunders.

National Consensus Project for Quality Palliative Care. (2018). *Clinical practice guidelines for quality palliative care* (4th ed.) Richmond, VA: National Coalition for Hospice and Palliative Care. Retrieved from https://www.nationalcoalitionhpc.org/ncp

Papadatou, D., Bluebond-Langner, M., & Goldman, A. (2011). The team. In J. Wolfe, P. S. Hinds, & B. M. Sourkes (Eds.), *Textbook of interdisciplinary pediatric palliative care* (pp. 55–63). Philadelphia: Elsevier/Saunders.

Robinson, M. R., Thiel, M. M., Backus, M. M., & Meyer, E. C. (2006). Matters of spirituality at the end of life in the pediatric intensive care unit. *Pediatrics, 118*(3), e719–e729. https://doi.org/10.1542/peds.2005-2298

Sourkes, B. (1995). Armfuls of time: The psychological experience of the child with a life-threatening illness. Pittsburgh, PA: University of Pittsburgh Press.

Sourkes, B., Frankel, L., Brown, M., Contro, N., Benitz, W., Case, C., … Sunde, C. (2005). Food, toys, and love: Pediatric palliative care. *Current Problems in Pediatric and Adolescent Health Care, 35*(9), 350–386. https://doi.org/10.1016/j.cppeds.2005.09.002

Steele, R., & Davies, B. (2006). Impact on parents when a child has a progressive, life-threatening illness. *International Journal of Palliative Nursing, 12*(12), 576–585. https://doi.org/10.12968/ijpn.2006.12.12.22544

Strada, E. A. (2018). *Palliative psychology: Clinical perspectives on an emerging subspecialty*. New York, NY: Oxford University Press.

Together for Short Lives. (2018). A guide to children's palliative care. Bristol: Together for Short Lives

Weisz, J. R., & Kazdin, A. E. (2017). *Evidence-based psychotherapies for children and adolescents* (3rd ed.). New York: The Guilford Press.

Wiener, L., McConnell, D. G., Latella, L., & Ludi, E. (2013). Cultural and religious considerations in pediatric palliative care. *Palliative & Supportive Care, 11*(1), 47–67. https://doi.org/10.1017/S1478951511001027

Wolfe, J., Hammel, J. F., Edwards, K. E., Duncan, J., Comeau, M., Breyer, J., … Weeks, J. C. (2008). Easing of suffering in children with cancer at the end of life: Is care changing? *Journal of Clinical Oncology, 26*(10), 1717–1723. https://doi.org/10.1200/JCO.2007.14.0277

Zadeh, S., Pao, M., & Wiener, L. (2015). Opening end-of-life discussions: How to introduce Voicing My CHOiCES™, an advance care planning guide for adolescents and young adults. *Palliative & Supportive Care, 13*(3), 591–599. https://doi.org/10.1017/S147895151400005