
Food, Toys, and Love: Pediatric Palliative Care

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Food, toys and love are what we need to live (4-year-old child).¹

Imagine—I was only eight years old when my brother died! Now I have to live with this for the rest of my life. . . (sibling).

How does one tell a bright twelve-year-old that he has a “life-threatening” disease (parent)?²

None of us can do this work by ourselves. I can go out to see the family in the home . . . but I need the team to come back to, to give me support, to give me ideas. You know there’s a saying: “It takes a village to raise a child.” Well, it takes a team to take care of a dying child, and a child with a life-threatening illness (hospice nurse).³

Pediatric palliative care is a new interdisciplinary frontier in the comprehensive care of children. While children with life-threatening and life-limiting conditions have always been part of the health care system, it is only now that an integrated vision toward their care is emerging. The underlying principles and ethics of palliative care are universal across the life span. However, as in all specialties, children bring with them unique issues and dilemmas.⁴ A child or adolescent with a life-threatening or life-limiting condition throws an assumed sequence out of

order. A time of role reversal is expected, when children will care for dying parents. When parents instead find themselves watching their child face the threat of death, imminent or not, any sense of order is shattered. Even before the child has become a differentiated individual through a natural developmental sequence, that child is wrested away. There is little preparation for separation by death when a psychological separation has not yet been effected. The adolescent who is beginning to negotiate an independent existence often seems especially hard to face when that “moving forward” is irreversibly halted, or at least disrupted.⁵

The critical importance of this new field was recently highlighted in the Institute of Medicine Report: *When Children Die: Improving Palliative and End-of-Life Care for Children and their Families*.⁶ Previously, several powerful publications had already set the stage for this seminal report: a thematic issue of the *Journal of Palliative Care (When Children Have to Die: Pediatric Palliative Care)*,⁷ a powerful statement by the American Academy of Pediatrics,⁸ the findings of two comprehensive British reports on children and young people with life-threatening and terminal conditions,^{9,10} and two earlier Institute of Medicine studies.^{11,12}

The Institute of Medicine Report⁶ in 2003 summarized the current evidence base of the field as follows:

Among the most common phrases in this report are “research is limited” and “systematic data are not available.” Research to support improvements in palliative, end-of-life and bereavement care constitutes only a tiny fraction of research involving children. Likewise, research involving children and their families occupies a small niche in the world of research on palliative and end of life care, which itself is small in comparison to other areas of clinical and health services research.

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The Pediatric Palliative Care Program at Lucile Packard Children’s Hospital at Stanford was established thanks to an endowment from John Kriewall and Betsy Haehl.

Curr Probl Pediatr Adolesc Health Care 2005;35:350-386

1538-5442/\$ - see front matter

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doi:10.1016/j.cppeds.2005.09.002

Thus, clinicians and parents must often make decisions about the care of children with little guidance from clinical or health services research. (p. 353).

The report itself put forth recommendations for future directions in the field (see *Toward the Future in Pediatric Palliative Care*, p. 383) and significantly galvanized new initiatives. Several articles, chapters, and books,^{6,13-23} both recent and forthcoming, attest to the burgeoning literature in the field.

This article will provide an overview of the clinical concepts, issues, and dilemmas in pediatric palliative care. Contributors to the piece include professionals from a spectrum of disciplines who comprise the Pediatric Palliative Care Program at Lucile Packard Children's Hospital (LPCH) at Stanford. Because an overriding theme in pediatric palliative care is the partnership of children, families, and professionals, we invited several families to contribute reflections on their own experiences. Through these multiple perspectives, we hope to communicate a nuanced view of the breadth and depth of the field.

Definitions

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision for respite, and care through death and bereavement (p. 9).⁹

In this definition from the British reports,^{9,10} "children" are defined not by chronological age alone, but rather, as the product of their chronological and developmental age, medical condition, size, handicap, level of cognition, and communication. "Young people" are broadly defined as ages 13 to 24, encompassing the period when many pediatric support services are no longer available. In a definition supported by the Executive Committee of the Children's Project on Palliative/Hospice Services (ChiPPS), the pediatric arm of the National Hospice and Pediatric Care Organization (NHPCO) "children" refer to fetuses, infants, children, and adolescents.²⁴

As this new field develops, there is much debate about the terms "life-limiting" and "life-threatening."^{4,9,10} "Life-threatening" is a broader concept, in that it includes illnesses for which cure is possible, although the threat of a fatal outcome exists (eg, childhood malignancies). Of course, an illness may begin as "life-threatening" and convert into a life-

TABLE 1. Percentage of total childhood deaths by age group (1999)

Age	Percentage
Neonatal	34.3
Postnatal	16.9
1-4 years	9.6
5-9 years	6.4
10-14 years	7.6
15-19 years	25.3

limiting condition, as when a child relapses and curative options no longer exist. "Life-limiting conditions" are those for which there is no reasonable chance of cure from the outset; even if children survive for years and decades, they will not live out a normal life expectancy.

The necessity for palliative care—the concept and the clinical approach—may emerge at different points in the illness trajectory, depending on the prognosis for the child, the decisions that must be made in choosing treatment options, and always, the provision of optimal quality of life. One of the foremost goals of the field is to initiate palliative care for children earlier in the illness trajectory—in a proactive manner—so that effective care planning for the entire family, with a particular focus on the healthy siblings, is a priority. Those who work with dying children know that they *live* with many levels of awareness, and that their pain and suffering, both physical and psychic, can be great.

Psychologist: If you could choose one word to describe the time since your diagnosis, what would it be?

Child: PAIN (See Fig 1).²⁵

Psychologist: Are you in any pain? Does anything hurt?

Child: My heart. My heart is broken.. I miss everybody (Fig 2).²⁵

Approximately 55,000 children (ages 0 to 19) die in the United States each year.⁶ Tables 1 and 2 describe the age groups and causes of these deaths.

Categories of Life-Limiting Illness in Childhood and the Curative/Palliative Relationship⁹

Until recently, adult palliative care has focused almost exclusively on individuals with cancer and HIV disease. The spectrum of illnesses that fall under the rubric of pediatric palliative care is far broader. It includes the following conditions⁹:

- for which cure is possible, but can fail (eg, cancer: irreversible organ failure)

TABLE 2. Percentage of total childhood deaths by major causes (1999)

Cause	Percentage
Short gestation	8
Complications of pregnancy	2
Placental cord membranes	2
Congenital anomalies	12
SIDS	5
Heart disease	2
Cancer	4
Respiratory distress	2
Unintentional injuries	22
Homicide and suicide	8
Other	33

- where there may be intensive treatment to prolong life and allow participation in normal activities, but premature death is likely (eg, HIV disease, cystic fibrosis, muscular dystrophy)
- where treatment is exclusively palliative and may extend over many years (eg, neurodegenerative diseases)
- where severe irreversible but nonprogressive disability may cause susceptibility to complications and likelihood of premature death (eg, severe cerebral palsy, brain, or spinal cord injury)





To reflect this vast heterogeneity of illnesses, flexible models of care must be conceptualized¹⁰ as shown in Table 3.

How Pediatric Palliative Care Differs from Adult Care

In addition to this broad spectrum of conditions and models, pediatric palliative care provides coverage throughout the trajectory of the child's illness, including respite as an important component. Other differences from traditional adult cancer-based end-of-life care include^{9,10}:

- Smaller numbers of dying children than adults mean that there is less professional expertise and underrepresentation of children in palliative care protocols.
- The heterogeneity of illnesses, many rare, requires the involvement of many disciplines and specialists.
- Many children have genetic diseases so that there may be more than one affected child in a family.
- The time course of some illnesses is extremely variable; pediatric palliative care may extend over years, even decades (thus, the crucial need for respite).

TABLE 3. Curative and palliative care relationship

Key	Curative	Palliative
		
	As the illness progresses the emphasis gradually shifts from curative to palliative treatment.	
		
	Highly technical invasive treatments may be used both to prolong life and improve quality alongside palliative care, each becoming dominant at different stages of the disease.	
		
	No cure is possible and care is palliative from the time of diagnosis.	
		
	At first it is not apparent that this will be a terminal illness and palliative care starts suddenly once that realisation dawns.	

(Color version of table is available online.)

- A broad developmental spectrum is represented, including changes in the individual child through time.

Barriers to Optimal Pediatric Palliative Care

The medical, psychosocial, cultural, and financial barriers to the delivery of comprehensive pediatric palliative care are many.^{26,27} Professionals and parents are unable or unwilling to make the transition from curative to palliative care when the two are seen as mutually exclusive. In such a rigid model, the equation of palliative care with "giving up" is easy to understand: it is where the expression "there is nothing more to do" originates. As the field develops, the push

toward the integration of curative/palliative approaches throughout the illness trajectory (where one predominates over the other at different points—and can fluctuate) is critical. The underestimation of children's experience of pain, coupled with a pervasive "opiophobia"²⁷ among parents and professionals, has been a major barrier to optimal care. Most hospice and other health care professionals in the community are unfamiliar with pediatric symptom management, and thus until very recently, have been ill equipped to handle children in their caseload. A vicious cycle has developed: children and their families become intensely dependent on their tertiary care center and do not turn to community resources or their local pediatrician for help; in turn, these personnel do not gain expertise in pediatric palliative care. In the last few years there has been a concerted effort to educate the hospice community in pediatric care.^{15,22,28} This has included not only didactic training, but also the opportunity for staff to prepare emotionally and to address their fears and vulnerabilities about working with children who are dying. In all settings, too little attention has been paid to the impact of ethnic and cultural background and beliefs on families' experiences in the pediatric palliative care.

Third-party payors are only beginning to recognize the benefits of an integrated approach, whereby palliative care team participates alongside the primary medical/surgical teams from an early point (if not the diagnosis itself) in the child's illness. Clearly, in the majority of cases, this involvement cannot be mutually exclusive with curative or life-prolonging care and will often exceed the "6-month" limit of the traditional hospice benefit.^{6,29,30} Waivers are required to ensure that children have access to an individually tailored care plan as they and their families navigate a myriad of health care services. At the present time, advocacy efforts at the state and federal levels (eg, Children's Hospice International, California Children's Hospice and Palliative Care Coalition)^{29,30} are dedicated to these efforts.

Ethnic/Cultural Considerations

It is imperative to incorporate a family's unique ethnic and cultural background into all aspects of the palliative care plan, regardless of setting.³¹ Some important areas to explore in this regard include the following: How does the family's ethnic, cultural, or

national background impact their experience at the hospital or with caregivers? Are they members of the dominant group in the medical environment or are they in the minority? Special attention must be directed to immigrant and minority families. Are there any cultural or linguistic barriers, overt or covert, affecting their experience? Is the family encountering any prejudice? What are their beliefs and values related to childhood illness, death, medical care, and family involvement? What are the unique roles that the patient/family and extended community play in this culture? For example, in some cultures where the father is considered the absolute decision-maker, it would be offensive to discuss critical medical information in his absence.

In areas such as California, with its changing demographics and complex mix of ethnicities and cultures, care providers cannot be expected to be experts in the background of all of the families they serve. However, through sensitive and thorough inquiry, important information can be gleaned that promotes therapeutic relationships based on mutual understanding and respect.

Needs Assessments in Pediatric Palliative Care

The systematic exploration of children and families' experiences on a broad scale leads to insights about the conditions necessary for optimal clinical care as well as program development. In the last few years, two groundbreaking needs assessments³²⁻³⁴ emerged that pointed out huge gaps in the care that we offer to these children and their families.

The Boston study³² (at the Dana-Farber Cancer Institute) focused on symptoms and suffering of children at the end of life. One hundred three parents of children who had died of cancer were interviewed. According to parental report, the children had experienced substantial suffering in the last month of life: 89% had suffered from at least one symptom, most commonly fatigue, pain, or dyspnea. Furthermore, treatment of the symptoms, even those amenable to improvement, was seldom successful (see Symptom Management, p. 373, for more details).

The LPCH studies^{33,34} focused on family and staff's perceptions of pediatric palliative care at this institution. We first interviewed 68 English- and Spanish-speaking family members of 44 deceased children

(varied diagnoses) regarding treatment, transition to palliative care, and bereavement follow-up, as well as 14 siblings who participated in discussion groups. Although the participants' overall responses were positive, several areas of unsatisfactory interactions with staff were identified: confusing, inadequate, or uncaring communications; unavailability of staff; preventable oversights in procedures or policies; failure to include or meet the needs of siblings; and inconsistent bereavement follow-up. Furthermore, a discrepancy emerged between the high degree of pain described and parents' perceptions that pain had been managed well. The impact of language and cultural differences on Spanish-speaking families' experiences of care was substantial, such that all the problems noted in general were much accentuated for this subpopulation. Most community hospice programs were ill-prepared to serve children and the absence of a coordinated approach resulted in inconsistent quality of care.

In the second phase of the study, 446 hospital multidisciplinary staff (attending physicians, residents, nurses, social workers, psychosocial support staff, and ancillary support staff) as well as community physicians responded anonymously to a written survey regarding expertise/comfort in delivering pediatric palliative care. Staff reported feeling inexperienced in communication with patients and families about end-of-life issues, transition to palliative care, resuscitation status, and symptom management. They described occasions when a child's pain could have been managed better. Over half the staff reported inadequate support for those who treat dying children and expressed a desire for a program that would offer such backup, both for themselves and for families. Staff referenced personal pain and lack of support as the most difficult aspects of caring for a dying child.

Albeit from mirror image perspectives, families and staff shared remarkably similar concerns regarding pediatric palliative care. Furthermore, family members' sharing of their experience and expertise had an unexpected impact at both the local and the national levels. Because of their involvement, they were asked to testify at the Institute of Medicine's Public Meeting and were cited throughout the published report.⁶ In addition, families are involved in the ongoing development of our pediatric palliative care program, as well as in a variety of educational ventures, including the Initiative for Pediatric Palliative Care (IPPC) training program²⁸ and ChiPPS.²⁴ Families' perspectives are sought and integrated into the best of these

educational programs and many other types of resources.^{35,36}

To bring these concepts to life, the following section of the article presents case histories of children and adolescents that encompass a range of conditions and time perspectives. A brief introduction to each story highlights the pivotal issues to be illustrated.

Children, Adolescents, and Their Families in Pediatric Palliative Care: Selected Case Histories

Matthew: 4-year-old Child with Brain Tumor (Home)

Matthew's story³⁷ illustrates an "ideal" of palliative care, whether pediatric or adult. He received services from a hospital "home-care team" analogous to what a community hospice would provide. Matthew had an oncologic illness with a series of remissions and relapses, each relapse diminishing the chance of cure. It had a somewhat predictable timeframe once cure was no longer attainable, and symptom management was relatively straightforward. There was good psychosocial support for Matthew and the family, and respect for family autonomy in the decision-making process. As a result of all these factors, Matthew was able to preserve "quality-of-life" time at home.

Matthew was a 4-year-old child who had been diagnosed with a brain tumor, an ependymoma, at the age of 2. He had undergone three surgeries, one course each of chemotherapy and radiation therapy, and had one good remission of 9 months duration. In February, it was decided that all curative treatment options had been exhausted. The parents elected to provide palliative care for Matthew at home, and in fact, promised him that he would not return to the hospital again. Matthew died in June.

In the palliative care plan for Matthew, pain management was a foremost concern, particularly relief of headaches and extreme photophobia. Matthew received increasing doses of morphine, as well as sedation for sleep at night. The severity of his symptoms decreased dramatically. The effect of successful pain management was reflected in his many drawings. For example, when Matthew was in pain, his typical drawings were of dark, scary monsters that hurt people. Once his pain was well controlled and he

became much calmer, one of his colorful pictures was about “jumping and rolling in the grass and picking flowers like I did last summer.”

The parents were taught basic physical therapy techniques and suctioning to relieve the discomfort of excess secretions. Although Matthew initially received feeding through a gastrostomy tube (he complained about hunger, although he would not swallow food), over the course of the months he began to eat again. However, the tube remained in place as a route for medications, as did his port access. Although Matthew spent most of each day in his parents’ bed, surrounded by toys, books, and videos, a specially adapted chair and stroller allowed him to sit at the family dinner table and at the computer, to take baths safely, and to be taken for walks outside. At one juncture, his parents reported with pleasure that he had begun to play again.

Throughout these months, the palliative care physician visited approximately every 2 weeks; the nurse weekly; and the psychologist (B.S.) weekly (for Matthew and the siblings). All the members of the team were available for frequent telephone consultation with the parents. The family’s clergyman maintained contact throughout. The family was intensely grateful for the months that Matthew was at home, when they, as part of the palliative care team, provided him with optimal care.

Juan: Adolescent with Cardiomyopathy (Intensive Care Unit)

The medical, familial, and cultural complexity of Juan’s care warranted numerous clinical care conferences as well as an ethics committee consultation. The majority culture’s view that an adolescent has the right to informed consent and decision-making diametrically opposed the clearly expressed wishes of Juan’s family. The staff grappled to come to terms with their values and beliefs. Ultimately, they were faced with the unfamiliar challenge of caring for a patient with a prolonged ICU course that focused on comfort and symptom management (ie, palliative care), rather than on rescue and cure.

Juan was a 16-year-old boy from Mexico who was diagnosed with refractory heart failure 3 months before his death. He had been completely healthy before that time. Juan lived about 4 hours from our hospital

with his two young adult brothers and two uncles. He initially presented with ventricular fibrillation and required placement of an internal defibrillator, after which he was discharged home. Juan then experienced a severe syncopal episode that necessitated readmission and eventual Pediatric Intensive Care Unit (PICU) care. He now had a severe cardiomyopathy that required aggressive management, as well as drainage tube placement to treat pleural effusions. For complex medical reasons, it was determined that Juan was not a suitable candidate for cardiac transplant.

Because Juan’s parents spoke only an Indian dialect, the use of conventional telephone interpreter services was limited. Working through Juan’s brothers and uncles, we were able to inform the parents by telephone of his dismal prognosis. Consent was eventually obtained from the family to have a Do Not Resuscitate (DNR) order in place and to provide Juan with comfort care exclusively.

Although Juan was aware of his diagnosis, his parents were adamant that he not be informed of his extremely poor prognosis. Juan’s older brothers supported their parents, repeatedly explaining that in their culture, it would be wrong to do otherwise. Their request defied the team’s belief that an older adolescent should have the information, and thus the right, to make his own decisions about his medical care. However, they gradually recognized that in Juan’s culture, the hierarchical nature of the family system and the process of decision-making differed significantly from the majority view in the United States. The language barrier made it even more difficult to ascertain whether Juan understood his condition or the options around certain interventions. For example, a chest tube that allowed fluid to drain assisted him in breathing; however, the tube itself was uncomfortable and Juan requested that it be removed. Although a palliative care model would likely accommodate such a request if the patient were fully informed, it was unclear whether Juan understood that the tube’s removal could hasten his death. Furthermore, in accordance with his family’s wishes not to inform Juan of his impending death, the medical team did not discuss the option of hospice care with him.

Juan was kept comfortable with pain control, drainage devices, and as much psychosocial and chaplaincy support as possible. He died peacefully on hospital day 43 in his PICU bed.

Brian: Infant with Hypoplastic Left Heart Syndrome Diagnosed Antenatally (PICU)

It took 7 months for clear and consistent communication about Brian's care to be achieved with this family. Until that time, different teams (and individuals on teams) had presented quite different, and at times conflicting, scenarios to them. There was no primary pediatrician to help the family interpret and synthesize the complex data and probabilities. Ironically, while in the midst of the most sophisticated interventions available, the parents were very much alone in trying to make decisions for their infant.

Brian was diagnosed in utero as having a single ventricle. Following prenatal counseling, the parents chose to continue the pregnancy and to deliver the child at a center where 30 to 40 stage 1 procedures for this heart defect are performed annually. The family was informed of the multiple stage operations and the fact that, even if all went well, their child's heart would never be normal. The cardiovascular surgeon, cardiologists, and intensivists provided all the information to the parents. Brian was resuscitated shortly after birth. He was taken to the operating room on day 5 of life for the first of many surgeries. The surgery went well; however, his postoperative course was exceedingly complicated, including recurrent bouts of sepsis and necessitating two additional (unsuccessful) operations to relieve pulmonary venous obstruction. The team was conflicted as to what constituted "futility." However it was not until Brian was 7 months old that the surgical and ICU teams (medical and cardiovascular) began to agree on a palliative approach to prioritize comfort over any further interventions. Finally, at 8 months of age, all life-sustaining interventions were withdrawn. The family was able to remain with Brian until his death 5 hours later.

Casey: Neonate with Severe Lung Hypoplasia and Thoracic Dysplasia Diagnosed Antenatally (neonatal ICU, home)

Casey's parents faced several critical junctures of decision-making after the uncertain antenatal ultrasounds: to resuscitate Casey at birth and initiate intensive care; to move Casey from conventional to high-frequency ventilation, and then to remove all intensive care measures; to continue Casey's feedings, and ultimately, to bring Casey home on hospice care.

Casey was diagnosed with severe lung hypoplasia and thoracic dysplasia on the basis of serial ultrasound examinations over the late second and third trimester of pregnancy. Because neither the diagnosis nor the prognosis could be given with certainty, his mother requested a full resuscitation at birth and initiation of intensive care. Casey was intubated in the delivery room and responded favorably to support with assisted ventilation. Once in the neonatal intensive care unit (NICU), however, support with conventional ventilation proved inadequate. Casey was placed on a high-frequency ventilator, which maintained normal or near-normal blood gases. After several days it became apparent that weaning to conventional ventilation or off assisted ventilation would not be possible, as each attempt to reduce mechanical support resulted in significant carbon dioxide retention. After lengthy discussions with Casey's family, his mother requested that assisted ventilation be discontinued and that his care focus on comfort measures. After removal of his endotracheal tube, Casey's mother wanted to attempt small, slow bottle feedings (instead of a nasogastric tube). Casey tolerated them well without any signs of discomfort or aspiration. Three days after discontinuation of intensive care, Casey's parents took him home. Care was provided with around-the-clock availability of the local pediatric hospice program. About 6 weeks after discharge, Casey died at home, as a result of slowly worsening respiratory failure. His parents felt that even in its brevity, Casey had "lived a life," and that they had shared his life with him.

The Team in Pediatric Palliative Care

Comprehensive pediatric palliative care demands the specialized contributions of individual disciplines to address medical, psychological, social, and spiritual concerns of the child and family.^{6,9,10} Whether the team is formally defined, or is a set of professionals who come together as needed for a particular child, 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. Thus the distinction between the concepts of "multidisciplinary" and "interdisciplinary" exists: the first denotes the numerous separate disciplines that assemble on a team; the second denotes their interweaving. One of the challenges for a well-functioning team is to promote a unified approach toward care,

while respecting and building on each profession's contribution. Families feel confused, even abandoned, when unexpected gaps or changes in the care plan occur because of miscommunication among professional caregivers. Regular contact, whether in individual or team meetings, by telephone or through written/electronic means, keeps everyone "up to speed," increasing the likelihood that the family will receive consistent information. A second challenge is to provide this knowledge-based expertise to the family within a context of ongoing accessibility and availability, thus communicating a sense of the team's abiding presence.

In providing this steady care for the child and family, professional caregivers may experience their own distress in a sort of parallel process.^{1,5,6,25,34} They can feel helplessness and anguish in witnessing children endure pain and suffering and may identify with the parents. This reaction intensifies when the caregiver is also a parent, especially if his or her healthy child is of the same age as the patient. For the caregiver who does not yet have children, the specter of a fatally ill child may loom threateningly.⁵ In a survey,³⁴ staff cited the *personal pain* of losing a child as the most difficult experience in their work with dying children. For all these reasons, the professionals who engage in this extraordinarily rich and demanding work articulate significant needs for support themselves.^{5,6,25,34} Otherwise, the toll of cumulative unresolved grief exacts a heavy toll in their personal and professional lives. A cohesive team and the opportunity for individual and group consultation are crucial for those who are intimately engaged in repeated cycles of attachment and loss with dying children and their families.

In the following section, we highlight the roles of individual professions in pediatric palliative care. Both their uniqueness and their commonalities are evident in the descriptions.*

Medicine

There are many roles that physicians play, depending on their specialization and setting of care for the child.

*The disparate length in the role descriptions in no way reflects a prioritization of importance. Rather, our "official" team members wrote detailed descriptions of their roles (as coauthors); the consultants gave us brief descriptions (acknowledged as contributors).

Primary care providers, usually the pediatrician or family practitioner, have often known the child and family well over time and can offer perspective on the present crisis in the context of past stressors. Through this relationship, the family is afforded stability and guidance through the medical system, and facilitation of communication with the team. These physicians can be both educator and advocate in synthesizing complex information from specialists to help a family choose among available options for a child's care. When a child is primarily at home, for either long-term palliative or end-of-life care, the community pediatrician can ideally be the family's primary contact, along with the hospice team. A crucial (and too often overlooked) role of primary care providers is in bereavement follow-up. The pediatrician or family practitioner who maintains ongoing contact with the family often serves as a secure anchor into the future for parents and siblings, both medically and emotionally.

Specialists often have the most precise knowledge about the expected course of a condition and consequences of various interventions. They may be most aware of what support is needed for the family, or when the usual supports may not be adequate. These physicians carry the burden of presenting balanced perspectives of curative, life-prolonging, experimental, and palliative options at different points in the child's illness—as it is through the lens of the specialists' knowledge and opinion that the lines separating possibility and futility in care are drawn. When a child's disease is multifaceted, it is often among specialists that disagreements in approach or views of prognosis arise, and where families may feel "caught" in hearing different messages from different teams. The specialist may act in a consultative role to the family and the primary care physician during times of acute illness or may coordinate a child's care—especially when the course of disease is complex and chronic over months or years.

Intensive (ie, critical) care physicians assume a central role in caring for the child and family during life-threatening episodes of illness and are often called on to navigate critical decision-making as the end of life nears. A child with any diagnosis may interact with an intensivist at multiple points in the illness process, and in most children's hospitals 80 to 90% of all pediatric deaths occur in the intensive care unit (ICU) setting.³⁸ Intensivist training so far has focused almost exclusively on "rescue" and devotes minimal

time to caring for a child who is dying or for whom further ICU care is deemed unreasonable. However, when the intensivist has determined within reason that the child will most likely die, then it becomes his or her responsibility to ensure that the family has the necessary information and support to make appropriate decisions and then to assist them in allowing their child a natural death.

Symptom management physicians come from varied backgrounds including family medicine, pediatrics, anesthesia, neurology, oncology, physical medicine and rehabilitation, and internal medicine. Many work in multidisciplinary groups (eg, on “pain treatment” or “supportive care” services), providing consultation to the child’s primary team. In many settings, the pain and symptom management physician works closely with a nurse to supervise and facilitate multispecialty involvement while providing direct care and education as necessary. The immediate goal is to achieve optimal comfort for the child and also to plan and advocate for future quality-of-life goals. The symptom management physician may assist the team, the patient, and family as they evaluate and weigh therapeutic options, along with risks and side effects of such interventions. Creative options are sought to mitigate side effects that could threaten the child’s comfort, thus allowing the parents to consider treatment options that they might otherwise reject.

Palliative medicine itself is emerging as a certified specialty. Although historically the focus had been on serving adults, the field has expanded to embrace pediatric care. Most of these physicians come from a background in internal medicine, family practice, oncology, anesthesia, psychiatry, and pediatrics. Their roles are multifaceted, including clinical (with particular expertise in symptom management), research, and teaching leadership. They are often program leaders in hospital and hospice settings. Currently, the American Board of Hospice and Palliative Medicine offers boarding in Palliative Medicine, and certification of palliative care fellowship programs was first announced in 2004. Pediatric representation is now occurring at all levels.

Nursing

The nursing staff on the “front lines” spends the most time with children and their families in the majority of palliative care situations. Many families

acknowledge that the nurses are pivotal in providing support to them, whether in an inpatient, outpatient, or home/hospice setting. Nurses in advanced practice roles, such as clinical nurse specialists and nurse practitioners, may also be part of the team. In addition to their educational and supportive roles, they can order medications and perform procedures such as bone marrow aspirations. On certain services, they carry a primary “caseload” of patients whom they follow closely with a physician.

The primary role of nurses in any setting^{39,40} is to provide hands-on care of the child. They assess the patient’s status and determine if interventions are necessary, inform the physicians or nurse practitioners, implement the changes, and then evaluate the outcome. Nurses bear crucial responsibility to ensure that the child achieves and maintains an optimal comfort level, as well as the best possible quality of life as defined by the patient and family.

Nurses identify, access, and refer children and families to a network or resources that may be of support in moving through the palliative care process. They serve as educators by teaching families how to provide the necessary care for their child (especially for home) and ensuring that they have enough information to make informed decisions.

Nurses are in a position to be strong advocates. Since they spend so much time with children and families, they often become a trusted sounding board for children and parents to confide their hopes, fears, and concerns. A crucial advocacy role is to ensure that the voice of the child is heard amid all the adults. Night-shift nurses often describe how children and families want to talk in the middle of the night, and how listening provides comfort and relief.

Nurses often have an acute sense of “timing” as to the families’ readiness to make critical decisions in the child’s palliative and end-of-life care. As a liaison to the medical team, they can make certain that the team understands and carries out the family’s wishes. The following example illustrates the integrative role of a nurse practitioner in a complex intensive care situation:

Over a several week period, I was involved in the transition of a 7-month-old child with hypoplastic left heart syndrome from extraordinary medical support (since birth) to end-of-life care (see Case History: Brian, p. 356). I worked with the key team members and the parents in planning this transition. The various physicians involved in caring for Brian confirmed that the parents had heard all the necessary information and

were ready to withdraw life support and allow natural death. My role was then to communicate the family's wishes to the day and night staff. Through this process, I developed a clear agenda for the care conferences and a timeline for their decision and ensured that both parents and staff were in agreement with the plan.

Most of these conversations took place at Brian's bedside. This location allowed the parents to be with their baby, and I could be a role model for his nurses in end-of-life conversations, as well as involve them actively in the process. We created a homier atmosphere in his PICU room by bringing in an adult-size bed so that Brian's parents could lie with him. When the direction of care changed so dramatically from life prolonging to palliative, some nurses, who had known Brian since birth, were initially distressed. However, over a 2-week period, their understanding of and empathy for the family's decision evolved. I consulted closely with the social worker, chaplain, and palliative care consultant to ensure that the ongoing needs of both family and staff were heard. Through this thoughtful, albeit difficult process, the family was able to transition Brian's care gradually and withdraw interventions that they now understood as futile. They were able to hold Brian for 5 hours until his death.

The home hospice nurse is often the primary health care provider in the last stages of the child's life. A particular closeness often develops; the nurse enters the family's home circle to provide care for the child, and the visits and calls occur frequently, even daily.

Social Work

Social work, with its traditional systems-based focus on family, community resources, advocacy, and counseling, provides an invaluable resource for children and families in pediatric palliative care.^{14,41} Social workers guide the families as they wade through the complexities of the medical system and the myriad of concurrent psychosocial challenges. They are also particularly mindful of the unique challenges faced by the care team in meeting these needs. The role of social work is multifaceted and may include any or all of the following aspects discussed below.

In the child's world, the family is the most central and enduring influence. The child's wellbeing is intrinsically linked to parents' or guardians' overall functioning.^{30,42} Screening, assessment, and referral of parents for physical, emotional, social, or health-risk behaviors that can adversely affect the health and emotional/social wellbeing of the child are critical to providing excellent care. The comprehensive initial and ongoing *assessment* of the patient and family identifies background, unique beliefs, cultural/spiritual practices, mental health issues, patterns of behavior,

coping, and communication styles, and resource needs. Social workers then translate this information to the care team in a comprehensive "package." Once the staff understands the unique makeup of each family, they are better poised to address and anticipate their needs and partner in attaining the best level of care for the child.

Social workers provide a critical link in *facilitating communication* between the patient care team and the family. They monitor the opportunities for and efficacy of information exchanged and often set up interdisciplinary care conferences as a forum for the team and family to meet. Social workers *advocate* for the needs of the patient and family while respecting and facilitating their relationship with the team. Advocacy may focus on issues including, for example: meeting a family's need for information, community resources, or interpreting services.

Social workers are experts in *identifying and helping to secure appropriate resources* to bolster the family's overall functioning. The *coordination of services* is an ongoing task to assure that care runs smoothly, preventing duplication and conflict of services. This function is often shared with case management. Along with other members of the team, social workers often act as a liaison with the child's school.

Social work is one of the few disciplines that follows the patient and family through all phases of the illness, death, and bereavement. Social workers provide *counseling*, offering insight and support through the process. When families fear returning home after a long hospitalization (leaving their network of care), the social worker often maintains ongoing contact with them. Having a *liaison between home and hospital* diminishes family's sense of abandonment and allows the care team to stay abreast of their functioning. The sense of isolation that so many bereaved families experience is somewhat mitigated when social workers (and other team members) stay in contact after the death of the child, either through direct support or through the mobilization of specialized resources.

The following case illustration highlights the multifaceted social work role.

Carlos was a mature, stoic 16-year-old Mexican boy who came to the United States with friends to work and send money back to his impoverished parents and four siblings. After a few months working in the fields, Carlos experienced progressively intense hip pain. He had first noticed the pain during his long and arduous border-crossing on foot. Carlos was initially seen in the emergency room of a community hospital and then

transferred to LPCH, where he was diagnosed with osteosarcoma. As part of his first visit, a Spanish-speaking social worker met with Carlos for an assessment. After she provided Carlos with education and reassurance about his situation, he opened up with important information that helped the team plan for his care. During his hospital stay, the staff characterized Carlos as “aloof” because he didn’t express the emotion that was typical of a teenager in his situation. He hardly spoke, but smiled and was always courteous to the English-speaking staff. Even with an interpreter present, he rarely asked for help. The social worker, who had developed a positive relationship with Carlos, soon recognized that he was not someone to “share his feelings.” Rather, Carlos stated that he was a man who put his faith in God and his beliefs and had to remain strong during this time, especially for his family. With permission from Carlos, the social worker contacted the Spanish-speaking chaplain, who developed a quick bond with him. Together, they educated the staff about Carlos’s manner of coping and beliefs and helped them respect his way, even if they continued to believe that disclosure of emotion would be “better.”

Carlos’s prognosis was bleak, and the physician requested help from the social worker in getting his mother to the hospital as soon as possible. She arranged for a visa with the American Consulate and found temporary housing and transportation through a local volunteer resource. Carlos’s mother arrived from her village in Mexico and was initially overwhelmed by the complexities of the hospital environment. She spoke no English, yet always gave the impression of listening attentively. The social worker helped her negotiate the hospital system and repeatedly reminded the team of the need for interpreters. Carlos was happy to see his mother, but remained silent about his own worries. His mother relied heavily on the social worker and chaplain for support. Carlos was hospitalized for much of the next 6 months. Although his fervent wish to return to work never proved possible, this goal sustained him until his last days. Carlos died in the hospital with his mother, the social worker, and one of his friends present. Before he died, he told them that he wasn’t scared and asked his friend to help his family if he could.

Carlos’s mother wanted him buried at home in Mexico. The social worker secured financial and volunteer resources both to transport Carlos back and for his mother’s return journey. The mother gave the social worker the number of a pay phone in her village, and at an agreed-on time, 3 weeks later, they talked. Carlos’s mother expressed her gratitude to the social worker, the chaplain, and the hospital for providing for her son. She stated that he was in God’s hands.

Psychology/Psychiatry

I felt much better because I knew that I had somebody to talk to all the time. Every boy needs a psychologist! To see his feelings (6-year-old child)!⁵

“You don’t look at me like other people do and judge my behavior. Instead you analyze my behavior and try to get to the root of it. Mostly you helped me get to the

root of it, and helped *me* handle it on my own. You can ask for your family’s support, wisdom, experience; but it’s not fair to burden them. I have an older sister whom I talk to, but at the same time, I don’t want to upset her. I don’t want to make her cry for me. I know that when I first met you, I didn’t want to talk about it. I wanted to handle it on my own. But that faded so quickly because you’re so helpless. You really do need somebody that can come in and help you (Katharine, adolescent).”⁵

As pediatric palliative care develops into a field of its own, there is a window of opportunity to define the parameters of optimal psychological care for these children (American Psychological Association Task force report on children and end-of-life [in preparation]).³⁷ Ideally, the psychological status of each child admitted to palliative care should be evaluated to plan for optimal care, in the same way as medical and nursing assessments are performed. The contribution of child psychology and psychiatry, as well as other mental health disciplines, provides specialized knowledge and skills. The specific and unique interventions include evaluation of the child’s psychological status; diagnosis of psychological/psychiatric symptoms and disturbance; role of psychotherapy and psychotropic medication; consultation to families and the team. The healthy siblings are included in this network of care. Thus, under optimal circumstances, psychological intervention can play a pivotal role in the integration of the child’s comprehensive palliative care plan.

However, the availability of psychological consultation in pediatric palliative care is often limited. 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 often missed. The challenge, under these circumstances, is for other members of the team to provide thoughtful emotional support for the child in a carefully planned manner. One must take into account the child’s need and expressed wish for such support beyond the family, as well as the level of comfort that the child has formed in relationships with members of the team (or even one particular individual). Emotional support comes in many forms, from an openness to listen and answer questions, to regular visits at expected times, to creative art and play activities that allow the child expression of feelings and concerns.

Knowledge of normal psychological development is essential in evaluating the impact of illness on the child. On the one hand, children are forced to confront life issues prematurely, and conceptualize things that would ordinarily lie beyond their grasp. On the other

hand, by being sequestered by the illness, they miss out on normal developmental milestones (eg, moving into the world of peer relationships). Adaptation must be judged by balancing the illness parameters in relation to normal development.

Although many psychological problems of the child with a life-limiting illness may be categorized as adjustment reactions, more severe psychopathology can emerge.¹ 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. While it is important not to overemphasize pathology in the child, there is also a risk in minimizing or not recognizing it. Furthermore, any psychological response, however benign initially, can freeze into a traumatic reaction under sustained stress.⁴³ Thus, the mental health professional must be able to assess the severity of symptoms, particularly in terms of intensity and duration, relative to the child's current reality. In addition to knowledge of normal development and psychopathology, the clinician must be well informed of the child's medical status and implications thereof (both symptomatic and prognostic). This latter requirement provides grounding in the child's life situation and is crucial for accurate and effective diagnosis and intervention.

Psychotherapy is the treatment modality unique to the mental health professional.^{37,44} Within its framework, the child seeks to integrate the facets of his or her life. Through words, drawings, and play, the child conveys the experience of living with the threat of loss and transforms the essence of his or her reality into expression. For some children, self-help techniques such as relaxation, guided imagery, and hypnosis may be integrated into the psychotherapy. (These techniques are not restricted to psychotherapeutic intervention and may be employed by other disciplines trained in their methodology.) Most children enter psychotherapy because of the stress engendered by the illness, rather than more general intrapsychic or interpersonal concerns.

Play enables the seriously ill child to "re-enter" childhood. In child psychotherapy, play is the crucial vehicle of communication. Trauma of any kind, including illness, can extinguish—at least temporarily—some children's capacity for play, or erode its range of expression into rigid patterns.⁴⁴ Within the context of psychotherapy, a certain restoration is marked when the child's play reveals its former vitality (see Matthew, Case History: p. 354). For older children and

adolescents, psychotherapy is a time "apart," to reflect, question, grieve, plan, and hope.

What does the child understand of the therapist's role, and of the psychotherapy process itself?¹ It is important that simple, nonthreatening explanations be offered to the child. Terms such as "the talking doctor" provide a functional description that clearly distinguishes the therapist from other professionals on the medical team. The anxiety about seeing a therapist can be allayed by explaining that all children who are ill have worries, and that the therapist can help with these problems. The concept of confidentiality, or privacy, should be introduced early, defining its meaning and its boundaries. Over time, even if not articulated, the child comes to understand the therapist's role in his or her care. For older children and adolescents, the concept of the "psych person" as a team member—albeit with special bounds of confidentiality—helps to diminish the sense of stigma.

On one of her clinic visits, Karen's physician asked her how she was feeling. She answered: "Medically I'm fine, but psychologically I'm not so fine, but I'll discuss that with my psychologist."¹

With the intrusion of the illness, the relationship between the child and parents organizes around the pivot of potential loss. Thus, it is critical that the therapist not intercede as a divisive wedge between them. From the outset, an ongoing alliance between the child's therapist and the parents diminishes this threat and optimizes the outcome of the work. Such collaboration is a *sine qua non* of the process.^{1,43} Because the parents must sustain the therapeutic work in the child's day-to-day encounters with both physical and emotional stresses, their role cannot be underestimated.

Family therapy can play a pivotal role in sustaining, strengthening, and repairing family resources. The profound and enduring impact of the child's illness on the family is addressed within this context. In no way does family therapy preclude or contradict the individual psychotherapy with the child. Rather, it affirms the family unit as a whole and provides a framework for healing.

Psychologists and psychiatrists, like social workers and chaplains, are available to staff members as well as to families. In addition to teams who request consultations, individuals may seek out the opportunity to discuss the interface between their personal and professional lives.

Chaplaincy

I was brought up to believe that life is a gift. God gives life as a gift with no strings attached. It should be a given, just to live. Then if you want to work to be different things, you work for that. But you shouldn't have to struggle just to live (adolescent).⁴³

The role of the chaplain varies as palliative care changes throughout the trajectory of the illness.⁴⁵⁻⁴⁹ For many families, the diagnosis of a life-limiting illness in their child brings shock and disbelief. To understand and make sense of the crisis is the task of the parents and the child who is ill, as well as the siblings and the extended family. For many people this experience raises spiritual and religious questions: "How could God be so cruel?" "Why has this happened to my child?" "What did my child or I do to deserve this?" Although these questions may be asked of many people, they are asked differently (and frequently exclusively) of a spiritual care provider. In the beginning stages of illness, an important task is identifying a family's resources—spiritual, religious, and emotional. The chaplain helps families to think creatively about how their spiritual community can support them and functions as a bridge between the hospital and their congregation. For some families access to their own community constricts with the progression of the illness. The spiritual care providers assist families in finding and making meaning of the illness and suffering and providing religious rituals and emotional support. However, each theological tradition's teaching (eg, God gives us experiences to test our faith or to teach us lessons) will have its own impact.

Within many religious communities there is an understanding of suffering as part of retributive justice, leading many parents (and some children and adolescents) to question: "Did my child get sick because of something I did?" "Am I being punished for something I have not done?" Consequently the role of the chaplain may be to help people describe and work through their fear of retribution from a theological perspective. Parents may express guilt and remorse: that they cannot make the illness go away; that they did not act sooner; that they might have contributed to a genetic and/or environmental cause of a condition.

Another universal theme is related to prayer and hope: "Does God hear me when I pray?" "How is God responding to my requests and hopes?" "Why is God not responding in the way that I want?" The painful

awareness that children are not *miraculously* cured is obvious at every stage of treatment—whether or not the treatment is of curative intent. Often the work of the chaplain is to *hear* this dilemma, and rather than trying to "fix it," become a compassionate witness to the experience.

What parents have conveyed to their children about their views of life and death is important information. The pastoral care provider might be the first person to say, "How do you understand what happens after we die, and how have you begun to teach your children about this?" For some families it is a relief to have someone raise the question; for others, it is a frightening possibility. Locating the family on that continuum is a sensitive process, often done collaboratively with social workers, psychologists, and other members of the team.

The role of hope is probably the most important spiritual issue that arises for people in every faith tradition (or no faith tradition). How we support people in their hopefulness and find ways of bringing hope to situations where hopes are limited is a huge part of working in spiritual care. No matter how sick a child, parents describe the need for hope in their situation in such statements as: "Although I know my child is dying, I'm still praying for a miracle" or "Although the team says there is no hope, I am not giving up." The faith and trust that many families place in their spiritual beliefs and caregivers is profound. Many children request to meet with a chaplain on their own and form enduring relationships. Spiritual/existential concerns emerge.

A teenager who had undergone a heart transplant had stopped taking his antirejection medications and was admitted to the PICU. This boy had consistently denied stopping, both to his parents and to the medical team. In a talk with the chaplain, he began to cry and admitted that, in fact, he had often been noncompliant. For him, the deepest sadness was not that he was so sick; rather, it was that he had lied. In his faith tradition, such lack of integrity was so wrong that he needed to confess to live with himself. After his confession, the teenager said that he needed to apologize to his physician. They paged the physician, and after an emotional discussion, the boy was at peace.

A dying 9-year-old boy asked the chaplain whether there was baseball in heaven. His greatest regret over 2 years of illness had been his inability to join the Little League team with his friends. When the chaplain assured the boy that a baseball league exists in heaven, he closed his eyes and rested for the first time in days.

Another component of spiritual care is supporting the professional team so that they can in turn support

the families. For the medical personnel in particular—and all the team in general—the move from curative to palliative care may be experienced as a “failure.” This profound sense of loss and regret, and the sadness in its wake, is frequently shared with the chaplain, whose role is to listen, attend, offer support, and share experiences of coping. Each loss experience is reiterated with each new loss, and such sharing with one another confirms how deeply we are all affected by the work. In some instances, discussions focus specifically on faith—or threatened loss of faith—issues.

Chaplains offer a wide array of services in pediatric settings. They include but are not limited to groups for staff, both ongoing “drop-in” sessions as well as groups for whole teams at especially difficult times (eg, death of a particularly loved child, a traumatic death on the unit); memorial services for children, families, and staff; individual staff consultations; and educational and awareness activities around different spiritual and religious traditions in the hospital community.

Child Life

Child life specialists play a vital role in reducing the impact of stressful or traumatic events on the child within the medical setting. They work with children and adolescents on both an individual and a group basis and develop the programs in the hospital and clinic playrooms. It is immediately evident on entering any pediatric setting that the playrooms offer the ill children (and siblings) immeasurable respite and enjoyment. Thus, the child life specialists provide both therapeutic intervention and social recreation (which has its own therapeutic value).

There was a playroom in the children's wing, a wide room full of light . . . and my friends and I passed many hours as families, cooking pudding for our dolls before they were due in therapy. Most of the dolls had amputated arms and legs, or had lost their hair to chemotherapy, and when we put on our doctors' clothes, we taught them to walk with prostheses, changing their dressings with sterile gloves. We had school tables and many books, and an ant farm by the window so we could care for something alive⁵⁰

Child life specialists use developmentally appropriate and enjoyable techniques with patients and their siblings. Young children benefit from play with dolls, real (or realistic models of) equipment, and picture books to familiarize themselves with aspects of their medical experience. Older children and adolescents

may be more easily engaged through conversation and the expressive arts. These professionals help the children to understand their (or their siblings') diagnosis, treatment, and prognosis, clarify misconceptions, and address issues salient to the child's “outside” life, such as the impact on peer relationships. By preparing children for particular procedures (for example, blood draws, scans, electroencephalography, and central line placement), significant reductions have been noted in both subjective distress (anxiety, pain) as well as associated financial costs (procedure and recovery time, sedation).⁵¹ Child life specialists also train the children in self-control techniques to alleviate distress during outpatient visits and inpatient stays. Their insights are integral to the team's understanding of a child's adjustment to the overall illness experience.

Importantly, child life specialists are sensitive to bereavement needs and can be instrumental in initiating “legacy activities” (eg, memory boxes, scrapbooks) with children, siblings, and parents. They also develop bereavement “kits,” including written resources around grief and loss, and materials for siblings, for the families to have after their child's death.

Rehabilitation

Occupational and physical therapy (OT and PT) are designed to help patients develop or regain functional skills impacted by illness or injury. No longer are “rehabilitation” and “palliative care” seen as mutually exclusive.⁵² Rather, as the range and creativity of rehabilitative services in palliative care settings grow, children have new avenues toward enhanced quality of life.

In pediatric settings, these therapeutic interventions engage children in activities that are purposeful and meaningful to each individual child. Children engage in a variety of activities, or “occupations,” every day, the three most common being self-care skills, school participation, and engagement in leisure or play activities. Necessary performance components include, but are not limited to: muscle strength, range of motion, endurance, fine-motor, cognitive, and psychosocial skills.

In palliative care, the OT and/or PT contribute to quality-of-life care of the child in a myriad of ways including: activities of daily living skills (ADLS) assessment, feeding and swallowing evaluation and treatment, positioning for comfort, mobility training,

upper and lower body strengthening and range of motion activities, nonpharmacologic pain management, energy conservation, equipment needs assessment, and helping patients cope through self-expression activities. Following is an example of how rehabilitation services were integrated into a child's palliative care plan.

Joshua, a teenager, who was receiving palliative chemotherapy, was referred to rehabilitation services by his physicians. They wanted him to get out of bed and engage in everyday activities.

When the OT met Joshua, he was very depressed. He spent most of his days lying in bed, with the curtains in his hospital room drawn. The first time she attempted to evaluate Joshua, he refused. He remained in bed with his back turned toward her and barely spoke. The OT continued to check in with Joshua daily. He would talk with her a little more each day, but still refused to get out of bed. When the OT asked if there was something in particular that he would like to do if he were feeling up to it, Joshua responded that he wanted to have a tea party! Never having had a party of his own, he thought a tea party would be especially fun and "very stylish." The OT told Joshua that she would help him plan the tea party, but that he needed to regain some of his functional skills first, including transferring out of bed in to a wheelchair, and specific self-care and self-expression skills. Joshua agreed.

A PT was also very involved in his rehabilitation program. Joshua set goals with her to get strong enough to get himself out of bed, propel his wheelchair, and eventually walk again. To help relieve some of Joshua's pain, the PT provided Joshua massage and practical relaxation techniques.

In his rehabilitation sessions Joshua worked on an exercise program to strengthen his muscles so that he could transfer out of bed. He regained self-care skills such as brushing his teeth and dressing independently. Joshua was provided with a journal in which he could express his thoughts and feelings. During the last 10 minutes of each therapy session, he worked with the OT on planning the tea party. With each passing day, Joshua's strength improved. Soon he was able to complete a variety of self-care activities without assistance. Joshua's depression also began to lift. By the time he had completed writing his invitations, Joshua was able to self-propel his wheelchair through the hospital hallways to hand deliver them to staff and patients.

By the day of the tea party Joshua had achieved all of his occupational and physical therapy goals. Joshua got out of bed and sat in a wheelchair during the party. He greeted guests and poured tea for them. Over 40 staff attended the party, including Joshua's doctors, nurses, and teachers.

The OT's last visit with Joshua took place in the PICU when he was dying. Although was very weak and required an oxygen mask to help him breathe, he smiled when she entered the room. Joshua lifted his oxygen mask to speak and told her that his tea party had been one of his best days ever.

Education

School-age children who have been diagnosed with life-limiting illnesses are *children* first and foremost. School is their "job"—and they fear how their schooling will be affected by their medical condition and treatment. As educators, it is our expectation that medically fragile children return to and participate in school for as long as is feasible, receiving whatever special accommodations are necessary. Far from the harrowing world of the medical center and the intensity of the family, learning provides a safe and "normal" haven. In addition to academic skills and social contact, special goals (eg, extracurricular activities, grade promotions, and most significantly graduations) hold students' interest and motivate them with a future vision.

Ten-year-old Katie vividly illustrated the importance of school. Just weeks before her death, she reflected that, over the 4 years that her life had been disrupted by hospitalizations and outpatient treatments, school was what she missed the most (Fig 3).

Coordination with a child's school is critical, whether done (ideally) by a hospital teacher or another team member if educational personnel are not available. Parents need information to initiate the Individual Educational Plan (IEP) process (to identify necessary accommodations and resources). School administrative offices and guidance counselors have resources specific to the local district; bookstores and libraries have more general resources. The pros and cons of school inclusion and homebound instruction must be addressed with parents, teachers, administrators, and older students, as well as arranging for the child's needs during absences (tutoring, modification of assignments). School personnel themselves need preparation to receive the child back to the classroom on topics including the immediate and long-term effects on learning of the child's medical condition and treatment; what if any special care the child may require at school; and how to prepare the class for the reintegration of the child. The school staff may be quite apprehensive, and affording them the opportunity to address their concerns will much facilitate the child's successful reentry. Some children's hospitals have established programs with the specific mission of helping medically fragile children succeed at learning and in school.

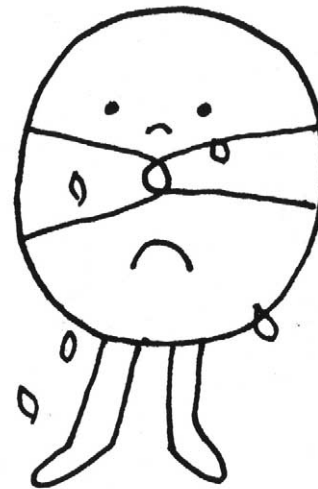
The following are examples of the importance of school for children living with life-limiting illnesses.



FIG 1. I felt as if the IV was exploding in my arm. (Note horizontal arm at bottom of drawing.)

Graham was diagnosed with a medulloblastoma at age 8. After surgery and a 3-month hospitalization, he spent a significant portion of third grade at home, receiving home teaching as assistance from the Returning to School Program at the Children's Health Council in Palo Alto. Before his illness, Graham had been an active, energetic participant in school, particularly drawn to imaginative play involving wizards and dragons, with his friends acting in the roles of heroes and heroines. A modified program was developed for Graham through the coordinated efforts of his family, home, and classroom teachers, as well as assistance from the Returning to School program at the Children's Health Council. Graham participated in school flexibly, to the degree to which he was able. Thus, he attended for part of each day during fourth grade; and in fifth, as his strength lessened, 1 or 2 days a week. Throughout this period, Graham spent hours drawing imaginary animals and developing story lines to act out with friends. His drawings reflected his passion for life and his astute sense of his own personal battle (Fig 4).⁵³

Graham's peer interactions kept his creative juices flowing, even as his strength ebbed. Exhibits of Graham's artwork (one of his goals) were mounted to great



from me to EVERYbody

FIG 2. From me to everybody.¹

acclaim at both the Children's Health Council and his elementary school. A few months after these triumphs, he died peacefully at home.

Angel, who has cystic fibrosis, was in and out of the hospital all of her life. A determined student, she relied on hospital and home teachers to help her get through high school. Because Angel was unable to attend her graduation, the LPCH School staff held a graduation ceremony for her in the hospital classrooms. Neither Angel nor many of those celebrating with her had dared to dream of this moment; too many of her friends had died before they completed high school.⁵⁴ Angel is now 21 and attends a community college. More of her friends have died in the past 3 years and she knows that she will likely not live to old age. Yet as she looks to the future, however long or short it may be, Angel feels that continuing to pursue an education has been one of the most important choices she has ever made.

Respiratory Therapy

Children receiving palliative care often require some type of respiratory support: from oxygen delivered via nasal cannula to significant positive pressure assistance to facilitate gas exchange. Depending on the child's underlying disease, the families feel that respiratory support is essential to ensure optimal comfort.³² The types of technology used will obviously depend on the child's condition and previous interventions. Some children with severe neuromuscular or chronic ventilatory problems may have a tracheostomy in



FIG 3. Katie: School is what I miss.

place for long-term ventilation. Others refuse this surgically placed airway and are maintained with noninvasive positive pressure ventilation (BiPAP). In addition to the delivery of oxygen and/or positive pressure, various breathing treatments may be helpful to mobilize secretions from the airway. Whether this level of treatment occurs in the hospital or in the home, the introduction of technology adds substantially to the burden of care of the patient. Education/training of the parents, and, whenever possible, home health care assistance are essential.

Pharmacy

A child requiring palliative care may need a variety of pharmaceutical interventions. In addition to symptom management, the child may concurrently continue on a complex therapeutic regimen. The hospital pharmacist's role is to assist the team in simplifying the different treatment regimens to facilitate outpatient or home care. The use of alternative dosing regimens, different routes of administration, different medications with similar pharmacologic properties, and ambulatory infusion devices may facilitate more independent care by the patient and family. In our Home Infusion practice we strive to transition patients from a dependent care model based in the hospital to an independent care model at home. Although often "behind the scenes" to the child, the pharmacist is a crucial core member of the care team. While pain and



FIG 4. Graham riding dragon.

other symptom management are not synonymous with pharmaceutical intervention, they certainly partner in the vast majority of instances.

Nutrition

Proper nutrition supports the growth and development of the child's body and brain, and it also helps a child tolerate treatment, metabolize medications, and reduce complications. Malnutrition resulting from illness or treatment can result in weight loss, fatigue, muscle weakness, susceptibility to infection, and disruptions in physical and mental development.

Typically, the nutritionist will monitor food intake to ensure appropriate consumption of calories, protein, vitamins, and minerals. Over time, as a child's illness progresses, goals may shift to hydration and weight maintenance, rather than weight gain. If a child is unable to take in enough nutrition by mouth, a nasogastric or gastrostomy tube may be needed to provide nutritional supplements (ie, enteral feeds). Parenteral support can be used in conjunction with tube feeding or used alone when the gastrointestinal tract cannot function.

Quality of life is a strong consideration when determining nutritional goals in palliative care. While nutritional support may prolong a child's life, the family may also feel that such support prolongs

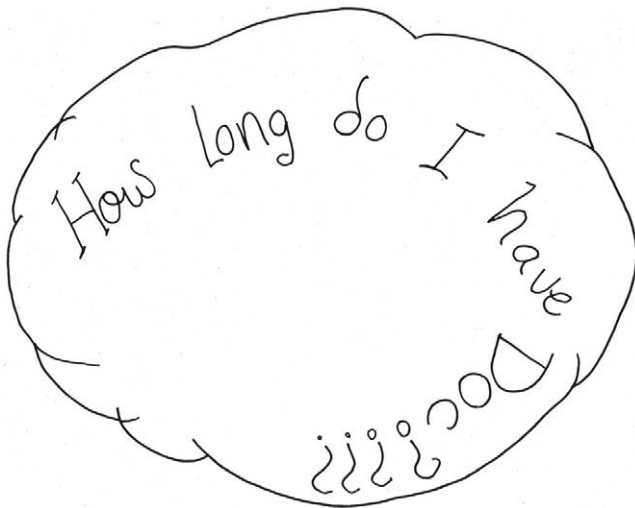


FIG 5. "How long do I have, Doc?"

suffering. Alternately, although a child may have reached end of life, they may request the continuation of sufficient nutrition to provide energy for interaction and play. In some instances, nutritional support contributes to an increased sense of wellbeing, thereby enhancing the time left in a child's life. Quality of life is also affected by the method of feeding. Nasogastric tubes may be anxiety-provoking or physically uncomfortable for children. Placement of a gastrostomy or jejunostomy tubes may contribute to feeling "over-medicalized" and families wishing to pursue comfort care may forego or terminate such aggressive support. Given that the nutritional plan depends on the combined goals of the child, family, and treatment team, ongoing communication and collaboration is crucial.

Interpretation/Translation

Families often comment that understanding the complexities of the medical system is like stepping into a foreign culture with its own language. The inability to speak or understand the primary language of the treating institution is an almost unimaginable stress. Even the simplest of communications becomes a challenge. The role of interpreters/translators in pediatric palliative care is one of both language and culture broker.^{6,33} In addition to being the communication bridge between the patient/family and the team, the interpreters have awareness and understanding of particular beliefs and cultural issues that may impact care. It is also critical to offer written materials (especially

consent forms) to patients and families in their own language. The translation of these documents is crucial to providing comprehensive and respectful care.

Case Management

Case management is a pivotal function in pediatric palliative care, where complex treatment plans and the need for a myriad of resources are commonplace. Case managers evaluate the patient and family's need for services within and outside the hospital and ensure that the proper funding to meet these needs is in place. A critical function of many case managers is to facilitate effective discharges by securing appropriate services within the community, thus creating a seamless transition to care at home.

Communication and Decision-Making with the Child

When I first heard my diagnosis, one question kept going around and around in my head: "How long do I have, Doc?" (12-year-old child; Fig 5).¹

Children usually live with a life-limiting condition over a prolonged period of months or years, if not a lifetime. Their knowledge, understanding, and awareness of their precarious life situation are often profound, at physical, cognitive, and emotional levels. The protective stance of the past has been that disclosure to children of their prognosis (and even, in some instances, the diagnosis) would cause increased anxiety and fear. Over the last two decades, however, a shift toward open communication has been evident. To shield children from the truth may only heighten anxiety and cause them to feel isolated, lonely, and unsure of whom to trust.¹

In communication with the life-threatened child at any juncture in the illness, "the truth is not a principle nor a duty nor a rule. The truth is an atmosphere of exchange, of listening, and of respect for the child and his needs. The truth is a state."⁵⁵ The precedent for a climate that enables such honest interchange is created from the time of diagnosis.⁵⁶ The individual child's competence and vulnerability serve as the context for decisions regarding disclosure at any point in the illness trajectory. Considerations about what, or how much to tell, include the child's age, cognitive and emotional maturity, family structure and functioning, cultural background, and history of loss. These same factors apply at the end of life, with extreme sensitiv-

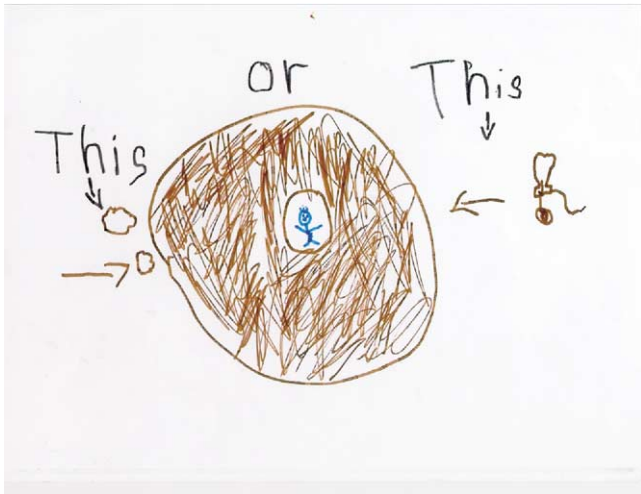


FIG 6. This or that. (Color version of figure is available online.)

ity to how the parents have chosen to inform the child throughout the illness experience, how the child has understood and processed information up to this time, and what the child is now asking—both implicitly and explicitly—about his or her situation.^{1,4}

One side of my head says: “Think optimistic.” The other side says: “What if this treatment doesn’t work?” (11-year-old child).¹

The child is often aware of the diminishing curative or life-prolonging options that he or she faces. It is at this time that the child may ask anxiously: “What if this medicine doesn’t work? What will you give me next?” Families are confronted by a series of decisions regarding the nature and intensity of medical interventions they wish to pursue. The team’s role is to clarify both experimental and palliative options and their consequences. In most instances, the parents make the decision; however, to varying degrees, the child and adolescent are involved in such discussions.⁵⁷⁻⁶⁰

During the last decade, there has been increased recognition of the child’s participation in making treatment decisions.⁶¹⁻⁶⁵ Crucial to this process is an assessment of the child or adolescent’s ability to appreciate the nature and consequences of a specific medical decision. This becomes particularly complex when the wishes of the child differ from those of the parents. Since actual assessment tools are only in the early stages of development,⁶¹ professionals must rely exclusively on their clinical judgment to assess children’s understanding of the contingencies they are facing. This is a juncture when input from members of

the interdisciplinary team is crucial: children often express their understanding, awareness, and thoughts about treatment options and living/dying to individuals other than their parents or primary physician.

Mikaela, a 10-year-old child with medulloblastoma, deliberated the pros and cons of continuing chemotherapy after a second relapse. She drew a picture entitled “This or This” (Fig 6). On one side of a doughnut she depicted tumor cells; on the other side she drew a needle for spinal taps. In the middle of the doughnut is a little stick figure of a person. At the time of drawing the picture Mikaela said: “I hate needles and spinal taps, but I also don’t want my tumor to come back. If I don’t have all the needles, then more tumor cells will grow. So if I don’t want them to grow, I have to have all those awful needles. That’s why I feel as if I am stuck in the middle of a doughnut.” Reflecting back on the drawing months later, Mikaela elaborated more explicitly: “What I mean by ‘I was stuck in a doughnut’ is that I had two choices and I didn’t want to take either of them. One of the choices was to get needles and pokes and all that stuff and make the tumor go away. My other choice was letting my tumor get bigger and bigger and I would just go away up to heaven My mom wanted me to get needles and pokes. But I felt like I just had had too much—too much for my body—too much for me So I kind of wanted to go up to heaven that time But then I thought about how much my whole entire family would miss me and so just then I was kind of like stuck in a doughnut”

In the following poem, 19-year-old Katharine reflects back on her diagnosis of osteosarcoma 3 years earlier. She explains her decision to have undergone a limb salvage procedure rather than an amputation⁵:

They say the fox will gnaw off his
own limb to save his life if
he gets caught in a trap,
but I have yet to see a three-legged
fox lazily browsing through an
apple orchard in late fall.
If his need for survival so greatly
exceeds his sense to maintain
the quality of his life, I
hail the fox.
I could not make such a sacrifice as he.
He will never run at full speed through
the yawning fields of the countryside
again.
Every time I see a fox so beautiful
and free,
I wonder how the chains of man’s
insensitivity can bind him
so snugly
that he forgets what it is to be
a fox.
And I feel sorry that the fox has
to make such a decision for
reasons, like mine,
which are beyond our control.

The poem just about sums up this experience: something beyond my control. The fox can't sit around asking why it's he. He must make the choice: either I cut my leg off or I die. The way I look at it . . . that's what it is to be me—to have both of my legs. If I had had my leg cut off without thinking, or without any choice, I know that I would have changed totally. But since I did have the option, I couldn't have it cut off. So you have to control what controls you to a certain extent Your independence, your self-respect: these are within your own control.⁵ (Katharine)

There are times that both older children/adolescents and parents feel that they have little control over their decisions, or that they are criticized for the choices they do make.

A 17-year-old adolescent with end-stage pulmonary disease was encouraged by the medical team to agree to a DNR order. The boy and his mother refused, wanting the team to pursue every available life-sustaining measure. Every day on rounds, the team tried to persuade them to change their minds, pointing out how much additional pain and suffering could be involved. Although their intention was caring, their persistence caused the boy and his mother to feel judged and unsupported throughout the remaining days of his life.

The Family System

I have a closer relationship with my family than most other kids because I've needed them more these last years (11-year-old child).¹

The child-in-the-family is a unit unto itself, with its own distinctive identity, strengths, and vulnerabilities. The myth that a child's illness either unites or destroys a family reduces complexity to oversimplification. In fact, resilience or vulnerability to the stress of the illness depends on a myriad of factors. A family's experience and means of coping with adversity in the past will, to some extent, predict its response in the present. Salient dimensions of family functioning, which must be viewed through a sociocultural as well as a psychological lens, include open/closed style of communication (both informational and affective); close/distant emotional involvement; flexible/rigid roles; organized/chaotic overall structure. How power and control are defined and delegated within the family, as well as how children are viewed (in terms of their individualism and competence), must be understood. Inextricably linked with all these variables are the nature and course of the disease itself.

From the outset, the child's definition of his or her "family" (both biological and psychological members) should be elicited. Without such information, the

caregiver's assumptions of inclusion or exclusion may be faulty, and valuable sources of support to the child may be overlooked. The nuclear family of child, siblings, and parents is at the core, surrounded by the extended family. In particular, grandparents frequently play a major role in the child's care. Close friends may be indistinguishable from "family," especially during crises. The child often names a pet as a family member—a relationship whose importance must not be underestimated. However, with the changing structure of the traditional family, and cultural differences in how family is defined, latitude must be made for alternative and complicated arrangements. These include, for example, immigrant families, where children and parents are geographically separated and children live with extended family; divorced and reconstituted (blended) families, with their inherent conflictual histories and new alliances; single-parent families; children of same-sex parents; and those living with grandparents or other family members.

Within a systems view, stress in one part of the family affects all the other members, in a sort of "emotional shock-wave phenomenon."⁶⁶ Children who are ill witness these reverberations and instinctively locate themselves as the cause. Guilt is a common response, even in the rational light of knowing that they did not ask for the illness to happen. The illness creates changes in all the preexistent roles and relationships within the family. Most common is the intensification of the relationship between the child and the parents (especially the mother), and the exclusion of the healthy siblings. The centrality of attention accorded to the child is understandable, and even necessary, during critical periods. However, when this focus becomes the norm over time, a complicated tangle of dysfunction can result. The child wields too much power, the marital dyad is disrupted, and the siblings lose their visibility in the family. While children are often aware of these imbalances, their own state of vulnerability and need overshadows these concerns.

The issue of "protection" within the family may emerge in various guises throughout the course of the illness. Children learn early that parents are neither omnipotent nor invulnerable, and that threatening forces operate even beyond their control. The parents, in mirror image, face their own utter sense of helplessness. As children try to spare their parents the intensity of their fear, anger, and sadness, so the parents attempt to shield the child from witnessing

their distress. Eventually a cycle is set in motion that isolates children and parents from one another at exactly those times that mutual disclosure could create a comforting bridge.

A 6-year-old child confided to the child life specialist: "I know I'm going to die, but don't tell my parents."

When discussing the challenges to long-term treatment planning, a 17-year-old stated, "My mom won't face the fact that I'm dying."

The Child Who Is Ill

If kids are normal, not sick, they like to be treated special. But if kids have a disease, they wanted to be treated normal. (11-year-old girl)¹

I just wish that I had armfuls of time (4-year-old child).¹

These opening statements capture the "double life" of these children. They long for the normalcy of daily life, at the same time as they live with the "abnormal" presence of illness and the acute awareness of time. From looking to feeling to being normal, the concept has implications for children's sense of competence and self-esteem. Parents have a formidable challenge from the outset in learning to treat their child "as normally as possible," especially with regard to discipline. Yet, their ability to do so communicates a critical message to the child: while the *illness* is abnormal, he or she is still normal in their eyes.

Whether the illness is a new or longstanding presence in a child's life, fearfulness may be a manifestation of its impact. Children who have navigated perilous waters in the medical environment may be reluctant to approach anything in the outside world that is not obviously "safe." Parents, in a parallel process to their child, also feel the effects of living with danger close at hand. Thus, apprehensive children are often acting out their parents' anxieties as well as their own. In older children and adolescents, an opposite pattern sometimes develops: that of risk-taking, of living on the edge when the future is uncertain.

School, as the defining structure of every child's day-to-day life, represents normalcy, a consistent and stable routine. Children understandably express apprehension about if and how their peers will accept them: will they tolerate "differentness"? Some children convert what could be the "stigma" of their condition into a badge of courage and fascination. It is not uncommon for children to maintain two categories of friends:

those from the "healthy" world of school and neighborhood, and those from the hospital, clinic, and special camps for children with similar conditions. Children who share the experience of illness demonstrate profound caring and empathy for one another. The threat of loss lurks, and when a child dies, the other children's grief has an acute poignancy.

Children's awareness of the implications of their illness can be conceptualized along a continuum.^{1,67} At one end, the child acknowledges being "very sick" or having a "bad disease"; however, there is no prognostic statement referring to life or death. In the middle, the child expresses some awareness that his or her life might be in jeopardy—uncertainty about *living*—but without a focus on death. At the other end of the continuum, the child is explicitly conscious that he or she could die of the illness. Awareness is a fluid, not a static state and is gleaned from many sources. Primary is the "wisdom of the body": the child's irrefutable recognition of how sick he or she is. Other cues include the child's knowledge of the illness, the urgency and intensity of treatment, the emotions of family and caregivers, and encounters with other patients. The illness ruptures the continuity between past, present, and future. This inability to take time for granted represents a crucial loss of innocence during childhood.

A 7-year-old girl who was being investigated for the possibility of recurrence of her disease drew a series of vivid rainbows. Each was placed centrally on the page, as a fulcrum between the sun on one side, and slashes of rain on the other. The child commented: "I don't know which side of the rainbow I'm on" (Fig 7).

Loss of control, identity, and overwhelmingly, of relationships—and the threat of these losses—are a part of these children's reality. A pivotal issue, not to say fear, is loss of control: over their bodies, over illness and pain, over emotions, over the passage of time, and ultimately, over life itself. All too often, caregivers label these children as "difficult" or "non-compliant." In most instances, clinical experience has shown that they are acting out their inordinate difficulty in coping with a sense of total powerlessness.

A 6-year-old boy refused his oral medications, required restraint for daily blood draws, and prohibited the medical team from examining him. The psychologist determined that several factors contributed to his difficulties: multiple, unexpected visits by staff he did not know; procedures done without any explanation of their purpose or forewarning before touching him; and no opportunity for him to make any decisions in his care. A plan was created such that visits by team members were

limited and scheduled; his physician and the child life specialist provided him with age-appropriate explanations of his illness and treatment; and the child was given the choice of which arm to use for taking his blood pressure, as well as which stickers he wanted after taking his medications. Within a few days, the child was entirely cooperative with his treatment regimen and demonstrated a dramatic decrease in anger, frustration, and anxiety.

Older children and adolescents are particularly sensitive to the impact of their illness or condition on their sense of identity. Physical manifestations, whether obvious or subtle, attest to the presence of disease, and so to the threat of loss.

When asked about cancer's impact on her life, a 19-year-old responded, "I wasn't like this before. I had interests. I went out with my friends. I used to take acting and dance classes. I had hair. I had goals. Now I can hardly get out of bed."

Loss of relationships—expressed through fears of separation, absence, and death—is paramount in anticipatory grief: "grief expressed in advance when the loss is perceived as inevitable."⁶⁸ Experientially, the process reflects the emotional response to the pain of separation before the actuality of loss. Anticipatory grief may show itself as the child's increased sensitivity to separation, without any specific reference to death; comments or questions related to death that may be seen as a type of preparation or rehearsal; and the undiluted and unmistakable grief of the terminal phase of the illness.

Therapist: What does it mean to be alive?
Child: That your family doesn't miss you. They miss you if you die. When you're alive, you don't miss people because they are right here.⁵

I don't want to be out of the picture (adolescent).

The distillation of anticipatory grief to its essence marks the imminence of death. At times imperceptibly, at other times dramatically, the child who has been living with the illness is transformed into a dying child. As the child confronts impending death, he or she may show signs of preparation. The child's actions or words are often quite matter-of-fact; their significance is not necessarily elaborated.

A 7-year-old girl had a recurrent dream: "In the dream, I want to be with my mother, and I can never quite get to her." The girl recounted the dream in a joint therapy session with her mother. Whereas the mother found the dream "excruciating," her daughter stipulated that "even though the dream is very sad, it's not a nightmare." The dream eventually provided the focal image for mother

and child to work through the anticipatory grief process.¹⁷

The endpoint of the terminal phase is often marked by a turning inward on the part of the child. Their cognitive and emotional horizons may narrow, as they conserve all their energy simply for physical survival. A generalized irritability is not uncommon. The child may talk very little and may even retreat from physical contact. Although such withdrawal is not universal, a certain degree of quietness is almost always evident. The child is pulling into him or herself, not away from others. If the parents understand this behavior as a normal and expectable precursor to death, they do not interpret it as rejection. They must be reassured that their contribution to the child's care and comfort—and most of all, simply their presence—are now the essence of the child's world.

The Healthy Siblings

It's no privilege having someone with cancer in your family. Of all the things I ever could have chosen, having my brother get cancer is not one of them.⁵

Please go talk to my sister. She needs someone to talk to. Do it as a favor for *me*. (adolescent patient to psychologist)

Although the healthy siblings live the illness experience with the same intensity as the patient and parents, they often stand outside the spotlight of attention and care. Professionals in the field of pediatric palliative care now articulate a strong mandate to focus on the siblings in their own right, both in the present and preventively for the future.^{6,69,70}

A group of siblings were asked: "Imagine that you are doing a campaign on behalf of siblings of children who are seriously ill. Draw a poster to illustrate your cause." The children drew an ill child in a hospital bed, surrounded by medical equipment, the parents at bedside. No siblings are present. They entitled their poster: "Don't siblings count too?" (Fig 8).

Sibling relationships are a crucial axis in the family, a subsystem of their own. All too often, the positive caring and devotion between the patient and siblings is underestimated and overlooked. Most children demonstrate an impressive capacity for concern about one another, even when ambivalence intensifies under the stress of illness.

The healthy siblings share common questions and concerns: some they raise with parents, professionals, or another trusted adult; others they harbor silently. Salient themes include the following^{69,70}:

- Siblings' "private version" of their brother or sister's illness, that somehow implicates themselves as a causative factor

Children, like adults, will supply a cause to fill in the gaps when they lack, or cannot fully grasp, information. Misconceptions and the confusion of coincidence with causality, combine with intense fear or guilt in an attempt to make sense of an overwhelming event.

- Effect of the visibility or invisibility of the illness and treatment process

An illness that leads to a dramatic physical change (eg, amputation) provides a visible focus for explanation. Yet, siblings may grapple with whether the patient is still the same person, despite the altered appearance. Young children may be puzzled by the invisibility of a condition (eg, leukemia) until visual cues (eg, hair loss) appear. The visibility/invisibility of the treatment process is a related issue. Siblings may perceive the hospital and clinic as threatening places, or they may envy these "outings," as the patient's chance for time with parents, and for missing school. They may not understand that, although "treatment" is a word with positive valence, the procedures, in actuality, can be dreaded and painful.

- Identification with the illness

The fear of becoming ill runs high among a sibling group. As children in the same family, past experiences that affected one child often affected another. Thus, when the siblings cannot stipulate, either cognitively or emotionally, a cause for the illness, the apparent randomness of events leads them to think, "Why not me, too?"

- Guilt and shame

Beyond the issue of causation, siblings at times feel guilty that they escaped the disease, and over time, that they develop further and accomplish more. Acknowledging their relief at being healthy only triggers the guilt more intensely. Rarely mentioned, but often lurking, is the unacceptable feeling of shame at having a "different" family, marked by a child who is ill, disfigured, or dying. In mirror image, the patient's protests of injustice ("it's not fair that I got sick and he didn't . . .") bring only short-lived relief, followed by remorse. Angry to be sick, the child resents the brothers and sisters for their health. Inextricable with

this anger is the child's guilt at his or her "monopoly" on the parents' time and energy.

- Siblings and their parents

The siblings may receive diminished attention and nurturance from their parents, especially when the patient is in the hospital. Older siblings who themselves are feeling deprived may resent stepping in as surrogate parents for younger sisters and brothers. Once the patient is home, siblings may resent the extra attentions and privileges accorded the patient; their complaint shifts slightly from that of "too little attention" to "preferential treatment of the patient." The parents are struggling concurrently with how to maintain equality and normality when, in fact, a distinctly "abnormal" factor in the family constellation exists. A painful issue is siblings' anger at the parents for not having been able to protect the patient, or even their perception that the parents (by commission or omission) played a role in the occurrence of the illness.

- Academic and social functioning

Siblings' concern with the patient's illness can affect two areas of daily functioning: school and peer relationships. Siblings' academic performance may be impaired because of their preoccupation, or they may focus on school to assure a sense of competence in the face of stress and helplessness. Similarly, siblings may curtail contact with their peers in their need for a family focus, or they may turn increasingly to their friends for support, or to flee the pain at home.

- Somatic reactions

Physical symptoms and sleep problems within a sibling group may develop as an expression of stress and distress or as a means of attracting parental attention. Preoccupation with their ill brother or sister may lead to carelessness about themselves, and thus, to accident proneness. In some instances, psychosomatic symptoms symbolically represent a sibling's concerns or fears (eg, the sibling of a child with a brain tumor who develops intense headaches).

Children who are ill may discover a new appreciation for the siblings' abiding presence and companionship. It is not unusual for them to declare that their sibling has been a "best friend" through the hardship. The children can provide each other a reciprocal resource of strength and comfort, unique from the intergenerational relationships in the family.

Symptom Management

We have come a long way in the area of pediatric symptom management, yet children's pain is still notoriously undertreated. Systematic evaluations published in the last few years demonstrate that children continue to suffer from pain and other distressing symptoms often and substantially.^{32,71,72}

The following story of Kristian illustrates the paramount importance of pain and symptom management in a child who lived over several years with an unrelenting chronic, life-threatening, and ultimately fatal condition. Five-year-old Kristian spent much of his life in the hospital receiving palliative care, although the term was not used at the time (1980s).

Kristian's working diagnosis was "Inflammatory Bowel Disease of Unknown Etiology." It was only discovered postmortem that he had Severe Combined Immune Deficiency Syndrome (SCIDS). Because Kristian had had all but 30 cm of bowel resected, he was unable to take anything orally. Although we did not have a Pain Management Service at the time, his pain was aggressively managed, using pharmacologic as well as non-pharmacologic interventions. He had a central line through which he received all of his medications, including opioids, muscle relaxants, tricyclic antidepressants (for chronic neuropathic pain), antibiotics, and benzodiazepines. He was on chronic total parenteral nutrition (TPN). By the last year of his life, Kristian needed as much as 1000 mg/hour of morphine to keep him fairly comfortable and functioning. Despite our own best efforts and ideas from experts worldwide, we were rarely able to make Kristian absolutely pain-free; at times he experienced unspeakable pain. Kristian's parents were taught to manage his lines, dressings, and chronic medications at home. They, along with his older brother and paternal grandparents, learned to help Kristian mitigate and cope with his pain.

He was followed regularly by the GI team, and by the neurology, infectious disease, and orthopedic services when necessary. Kristian and his family worked on an ongoing basis with the chaplain, psychologist, teacher, social worker, physical and occupational therapists, and music therapist. Numerous staff members supported them through their distressed as well as their joyful times. Kristian died in our hospital, surrounded by his loved ones, as his family had wished. In the hours after his death, staff from all areas of the hospital came to say good-bye.

Wolfe and colleagues³² evaluated the suffering at end of life of children with cancer. Parents identified the symptoms most frequently experienced by their child, as well as the perceived suffering related to the specified symptom. According to parents, 89% of their children suffered "a lot" or "a great deal" from one symptom or more in their last month of life. These symptoms were most commonly fatigue, pain, and

dyspnea; although poor appetite, nausea, vomiting, constipation, and diarrhea were also problematic. Not all children were treated for their symptoms. Of those with the most common symptoms for whom treatment was attempted, parents reported satisfactory improvement in only 27% of those with pain and 16% of those with dyspnea. The reasons for poor symptom outcomes are not fully clear at this time and may be multifactorial. In this investigation, the perception that the physician lacked involvement in the child's care at the end of life appeared to be correlated with a child having suffered a great deal from pain. Yet other parents have reported that health care professionals did everything possible to relieve distressing symptoms such as pain in their dying child³³ even as 54% of staff from the same institution caring for children at end of life over the same time period reported feeling inexperienced in pain management.³⁴ Children's ratings of their own symptoms and their evaluation of the type and quality of attempted interventions are a critical focus for future study.

Some of the barriers to better pain management for children with life-limiting illness are seen routinely in practice. Children often require far larger doses of medication than those recommended in standard drug manuals. Misconceptions about the frequency of drug addiction and respiratory depression (on the part of both professionals and parents) lead to the imposition of artificial and unnecessary limits in the therapeutic plan. An inadequate understanding of the pharmacodynamics and pharmacokinetics of analgesics, inadequate assessment and treatment of psychological and spiritual distress, and lack of understanding of the ethics of pediatric end-of-life care also contribute to poor pain management. Too often, the dying process is more distressing and traumatic for children and families than necessary.^{26,27}

Symptom management in palliative settings considers a child's holistic experience of illness and health, as it rests in the larger context of the family.^{73,74} Our mandate is to "stand with" a child and their family during this time of crisis and transition. The American Academy of Pediatrics stated that "the goal of palliative care is to add life to the child's years, not simply years to the child's life."⁸ Symptom management, then, focuses on the most fundamental of a child's needs: to restore, maintain, and support quality of life whether or not curative treatments are continuing.

The first step involves careful attention to understanding the distressing symptom fully. History-tak-

ing, physical examination, and (at times) additional testing are all necessary components. Direct intervention to treat the cause is often begun immediately. Pharmacologic, nonpharmacologic, and cognitive-behavioral strategies may all be used even when the cause of a particular symptom remains elusive, or its treatment is partially or totally refractory to primary intervention. For pain, opioid analgesics form the cornerstone of therapy for moderate to severe symptoms, although nonsteroidal antiinflammatory drugs and specialized adjuvants are also routinely used. Treatment of other symptoms may involve specific drug intervention. These medications are most often prescribed based on evidence from adult trials because pediatric studies are so few. Medications can be formulated into suppositories or transdermally absorbed creams if a child cannot tolerate delivery by other routes. Nonpharmacologic and cognitive-behavioral strategies include biofeedback, acupuncture/acupressure, transcutaneous electric nerve stimulation (TENS), hydrotherapy, massage, distraction, guided imagery, hypnosis, progressive relaxation, and meditation. Traditional forms of psychotherapy (both play and verbal) as well as expressive and pet therapies can also be effective.

Psychological symptoms in seriously ill children are often multiply determined and in flux. Physical pain, metabolic imbalance, neurologic dysfunction, infection, and the impact of medications are closely linked, if not at times inseparable from psychological distress. Most common are diagnoses in the broad categories of adjustment reactions, anxiety, and depression. Anxiety represents a widely diverse group of developmentally appropriate and pathological coping responses, ranging from preexistent anxieties exacerbated under the stress of illness, to cumulative generalized anxiety, and even posttraumatic stress disorder. Yet, sleep deprivation and delirium may present as anxiety and agitation. The psychological and somatic symptoms of depression can be hard to differentiate from effects of the illness and treatment. Furthermore, there is often confusion between sadness/anticipatory grief and clinical depression: what is a “normal” response to impending loss versus the “symptom” of depression that should be treated with psychotropic medication? Psychotic and organic brain syndromes often present with cognitive and perceptual disturbances. Delirium may also present as anxiety or oppositional or aggressive behavior; parents frequently report sensing something is “different” about their child, but are unable to

describe specifically the change. It is for reasons such as these that definitive psychiatric diagnosis can at times be elusive. As a result of these diagnostic ambiguities, one often proceeds with psychological or psychotropic intervention on the basis of managing specific symptoms rather than treatment of a presumed underlying psychiatric disorder.

Table 4 lists some of the common symptoms and treatments used for children in palliative care. Although a comprehensive presentation of symptom management techniques is beyond the scope of this overview, the reader is referred to resources that guide the practitioner in treatment strategies.^{15,16,28,75-77}

Ultimately, to offer palliative care is to care. The word “care” derives from the Gothic “Kara,” which means to lament.⁷⁸ To care then is to grieve, to experience sorrow, to “cry out with.” We have an ethical, professional, and human responsibility to stay present to the experiences of these children and families and to mitigate their suffering to the greatest extent possible. Although we do not always have the power to change the course of a child’s condition, we can offer the best of our collective knowledge of symptoms and their management.

Setting of the Child’s Death

For some families, there is the possibility of planning ahead and choosing a setting for their child’s death—home, hospital, or hospice. While there are many freestanding pediatric hospices in the United Kingdom, used for both respite and end-of-life care, George Mark Children’s House is the first in the United States. It opened in San Leandro, California in 2003. It was modeled on Canuck Place Children’s Hospice in Vancouver, Canada, the first in North America, that had opened in 1995. Several more pediatric hospices are works-in-progress in North America as well as around the world.

The child may express a preference about where he or she feels “safe” or prefers to be. Clear information about how the child is likely to die and professional support to validate the family’s choice are crucial. Even more important is the explicitly stated “permission” from all members of the professional team that the family may change their choice freely at any time—that all options remain open and that no decision is irrevocable. While in the current culture of palliative care there is strong advocacy for children to

TABLE 4. Common symptoms experienced by children with life-threatening illness and management options

Symptom	Management option
Pain	<p>Assess quality, frequency, duration, and intensity of pain; reassess efficacy of interventions</p> <p>Prevent pain when possible by limiting unnecessary painful procedures, giving preemptive treatment prior to a procedure (eg, including sucrose for procedures in neonates)</p> <p>Treat underlying cause if possible, weighing benefits versus risks to treatment</p> <p>Consider/treat coincident anxiety and lack of control</p> <p>Medications: Opioids (eg, morphine, hydromorphone, fentanyl, methadone, hydrocodone, oxycodone, codeine), Nonopioid analgesics and NSAIDs (acetaminophen, ibuprofen, ketorolac, naproxen, etc.), adjuvants, and other medications (tricyclic antidepressants at low doses (eg, amitriptyline, nortriptyline) trazodone, antiepileptics (eg, gabapentin, carbamazepine, topiramate), local anesthetics (eg, lidocaine, prilocaine, bupivacaine), ketamine, baclofen, cyclobenzaprine, sucralfate</p> <p>Nonpharmacologic strategies: guided imagery, relaxation, hypnosis, art/pet/play therapy, acupuncture/acupressure, biofeedback, massage, heat/cold, hydrotherapy, stretching, yoga, transcutaneous electric nerve stimulation, encourage enjoyable recreation/activities, distraction, routine/structure</p>
Dyspnea or air hunger	<p>Suction of secretions if present, positioning, comfortable loose clothing, fan to circulate air</p> <p>Educate/reassure family about "death rattle," uneven, irregular, and deep respirations near end of life</p> <p>Limit volume of IV fluids, consider diuretics if fluid overload/pulmonary edema present</p> <p>Antibiotics (if pneumonia present)</p> <p>Consider treating anemia if present</p> <p>Oxygen via non/least distressing delivery mechanism</p> <p>Behavioral strategies including breathing exercises, guided imagery, relaxation, music</p> <p>Medications: opioids (as above), sedatives/anxiolytics (eg, benzodiazepines), antimuscarinics (eg, atropine, glycopyrrolate), expectorants (eg, guaifenesin)</p>
Fatigue	<p>Sleep hygiene</p> <p>Medications: stimulants (eg, dexedrine, dextroamphetamine), short-acting medications to restore sleep cycle (eg, zolpidem, zaleplon)</p>
Nausea/vomiting	<p>Limit causative medications if possible</p> <p>Consider dietary modifications (bland, soft, adjust timing/volume of foods or feeds)</p> <p>Aromatherapy; peppermint, lavender</p> <p>Acupuncture/acupressure</p> <p>Medications: ondansetron, granisetron, metoclopramide, scopolamine, dexamethasone, promethazine, lorazepam, diphenhydramine, dronabinol</p>
Constipation	<p>Increase fiber in diet, encourage fluids</p> <p>Prevent: start stimulant + softener whenever starting constipating medications such as opiates</p> <p>Medications: eg, polyethylene glycol-electrolyte solution, docusate, senna, glycerin, bisacodyl, milk of magnesia, magnesium citrate, mineral oil, sodium phosphate enema</p>
Pruritis	<p>Consider cause, opiate rotate if severe/related to opiate</p> <p>Moisturize skin</p> <p>Trim child's nails to prevent excoriation</p> <p>Try specialized anti-itch lotions</p> <p>Counterstimulation, distraction, relaxation</p> <p>Medications: sedating and nonsedating antihistamines (eg, diphenhydramine, hydroxyzine, cetirizine, loratadine, fexofenadine), nalbuphine if opioid related</p>
Diarrhea	<p>Evaluate/treat if obstipation</p> <p>Assess and treat infection</p> <p>Medications: eg, loperamide, diphenoxylate and atropine, bismuth</p>
Depression	<p>Psychotherapy, behavioral techniques</p> <p>Medications: selective serotonin reuptake inhibitors (eg, fluoxetine, sertraline, paroxetine, citalopram), bupropion, venlafaxine</p>
Anxiety	<p>Psychotherapy (individual and family), behavioral techniques</p> <p>Medications: anxiolytics (clonazepam), antidepressants (see those listed under depression)</p>
Agitation/terminal restlessness	<p>Evaluate for organic or drug causes</p> <p>Educate family</p> <p>Lighten or deepen sedating medications based on child's need for control</p> <p>Medications: benzodiazepines (eg, lorazepam, midazolam, diazepam), haloperidol, phenobarbital</p>
Seizures	<p>Position patient for safety during involuntary movements</p> <p>Benzodiazepines (eg, lorazepam, diazepam) Antiepileptics (eg, phenytoin, phenobarbital, valproic acid)</p>

die at home, professionals must bear in mind that, for some children and families, the hospital is a better option, and that choice must be respected. Siblings are rarely included in these discussions and thus are often inadequately prepared for the eventuality of a child dying at home.

Critical End-of-Life Decisions⁶⁵

There are two types of patients who die in the PICU: those who were previously healthy and have recently experienced a catastrophic event (eg, motor vehicle accident, life-threatening infection such as meningococemia), or those with a severe chronic illness that is now terminal (eg, cystic fibrosis, malignancy, major congenital malformation). Many of the children in the latter category would be better served in a non-ICU hospital setting, or at home with hospice care. The intensivist has typically had the most experience in end-of-life care for those who were previously healthy and are now in the process of dying.

As the child's condition worsens, or further life prolonging or curative care is deemed futile, the goals should transition into a palliative mode, with an emphasis on comfort and compassion. How is this achieved, particularly in an intensive care setting? Building consensus with the various medical teams involved in the care of the child is a challenging task. Once all the medical and surgical services agree that further intervention will not benefit, and may even cause harm to the child, the responsible physician must communicate the rationale for the new direction of care to the rest of the team and family (and child if appropriate).

Systematic and regularly scheduled care conferences are an important vehicle for these discussions, both for the staff among themselves and with the families. We promote a multidisciplinary approach coupled with primary nursing to enable as unified a presentation as possible to the family. Agreements are almost always reached without the involvement of ethics committees and the legal system. Discussions with the family are usually better held in a room separate from the child's. Depending on the parents' or guardians' preference, family members, friends, or other individuals important to the family are welcome to attend. Some families choose to record the conversation or take careful notes. As appropriate to age, developmental level, and awareness, older children and adolescents may play a role in these discussions.

Once the family has reached consensus with the medical team, the transition to end-of-life care to be provided in the ICU setting is instituted.^{65,79-84} Implementation of this change usually begins with discussion regarding limiting further aggressive treatments (ie, to restrict the use of unusual forms of ventilatory support, or not to escalate further cardiovascular support). Once these new limits have been agreed on, it stands to reason that the child's resuscitation status must be readdressed. DNR does not mean to give up on the child or to diminish the child's care. Rather, it specifies what would happen in the case of a cardiac arrest or if the child's respiratory status continued to deteriorate. Families are reassured that their child will be kept pain- and anxiety-free at all times. We also discuss with the family which individual staff members they would want present when active life support is withdrawn. In addition to medical and nursing personnel, families often request that a mental health professional, chaplain, or interpreter be with them.

Once a decision has been made to institute withdrawal of active life support, families differ with respect to their involvement in the transition process. Some families want to be active participants, remaining in the room, and even holding their child while the endotracheal tube is removed and the vasoactive medications are reduced. Others prefer to leave for these procedures and return once their child has been completely separated from the ventilator.

The trajectory of these procedures is fairly standard for children who are brain dead. However in those patients who do not fulfill brain death criteria, the family must be informed that, after withdrawal of active support, the time of death is indeterminate, as is the course that the child's condition may take.⁸⁴ In addition, the family should know that the child may demonstrate a variety of breathing patterns during this transition toward natural death that may seem to indicate struggle or distress (eg, complete apnea, periodic breathing, gasping, altered—at times bizarre—respirations), but are in fact normal. Both opioids and benzodiazepines will be administered as needed, and the child will be sedated to the point of maximal comfort.

Every effort should be made to have a private room for the child and family, as well as to shield other patients from this event. The monitors may be discontinued, and the family is encouraged to be in the room with their child. Some centers have created a warm room, like a family space with couches and music.

This environment permits a high level of care delivery, yet creates a gentle environment for the child's final days, and for the family to stay with their child after the death. It is not uncommon for the family to spend hours in this room saying their final good-byes, feeling the reassurance of the staff nearby.

Before the point of allowing natural death, the attending physicians should broach the issues of autopsy and organ donation. After the child has died, these issues often arise again, along with questions about funeral arrangements.

Occasionally, a child's condition will not progress to death despite the withdrawal of life supportive measures and the child survives in a severe and debilitated condition labeled a persistent vegetative state (PVS). This is a state of perpetual unconsciousness in which there may be minimal neurologic responsiveness to some external stimuli and the maintenance of vital signs (heart rate, blood pressure, respirations, and temperature). Some of these patients are eventually cared for in the home or in specialized long-term nursing facilities. Patients with PVS are susceptible to infections, and death usually occurs as a result of pneumonia, urinary tract infection, or complications of skin infection.^{65,81} After many months or years of caring for a child in PVS, a family may decide to limit various treatment modalities and opt for a more palliative strategy. The physicians caring for these children should be prepared to work with their families in establishing advanced care directives for them.

One of the most frightening and difficult situations to deal with is the "locked-in-syndrome."^{65,81} Here the outward signs of responsiveness are lacking, owing to paralysis, muscular dysfunction, or acute neurologic insult, but unbeknownst to observers, consciousness persists. This condition is seen in injuries to the lower brainstem where the neocortex has been spared. It must be suspected and ruled out before any definitive pronouncement of neurologic unresponsiveness is made that could lead to withdrawal of support and death of the patient.

Although there are many ethical issues surrounding end-of-life care, one of the most controversial, on both personal and professional levels, is the withholding of nutrition and hydration. Most health care professionals in the hospital setting continue to believe that patients should at least receive appropriate hydration and some caloric intake at the end of life.¹⁰ However, as the body prepares to die, much of one's own metabolism begins to slow to the point that providing fluids and

calories only prevents a natural death from occurring sooner. A gastric feeding tube (via nose or mouth or a surgically placed gastrostomy) can necessitate painful procedures which may require medication to calm the patient. If the patient requires life-sustaining or life-prolonging intravenous fluids, pain associated with attempts to obtain vascular access will occur. Studies on the metabolic needs of the child before death are needed. Only with this information will the ethical issues focus on symptom management, rather than personal beliefs that hydration and nutrition must be provided to the dying patient.

Providing the appropriate medical, psychological, social, and spiritual support during these extremely difficult transitions has proven to be most helpful to both the child and the family as well as to the health care team. Whenever possible, the palliative care team should review and evaluate the process. Each family situation is unique and deserves close and sensitive attention.

Bereavement

Parenting is a permanent change in the individual. A person never gets over being a parent. Parental bereavement is also a permanent condition. The bereaved parent, after a time, will cease showing the . . . symptoms of grief, but the parent does not "get over" the death of a child.⁸⁵

Your brother or sister will always be in your heart. (8-year-old bereaved sibling) (Fig 9).⁸⁶

*Webster's Dictionary*⁸⁷ defines "bereaved" as "a word derived from 'reaved' or 'reft' meaning: to deprive and make desolate, especially by death." Bereavement is a process that ebbs and flows over a lifetime. Certain experiences in the bereavement process are relatively universal; however, in many ways it is a highly individualized experience dependent on many factors. These include developmental level, psychological history (particularly coping with past losses/trauma), family composition and background, ethnicity, culture, spiritual beliefs, and available support.⁸⁸⁻⁹⁰ Individuals in the same family grieve in different ways and on different "schedules," thus the loneliness that couples often express when one member is not "in sync" with the other, despite the fact that they are mourning the same child.⁹¹⁻⁹⁶ As for children, their mode of expressing grief may differ substantially from adults', and thus, its meaning and depth are often underestimated, or even missed completely. They become "disenfranchised grievers"⁹⁷ admonished to

“be strong for your parents” with little acknowledgment of their own unique mourning process.^{69,86,97-100}

Bereavement follow-up by the professional team is an intrinsic component of comprehensive pediatric palliative care.^{6,101} Families often express the sentiment of a double loss: first and foremost, the loss of their child, as an individual and as a member of the family and the greater community. Second, compounding their grief and disorientation, they mourn the loss of their “professional family”—the treatment team whom they have known and trusted, often over months and years.^{6,33} Contact from a team member after the child’s death not only assuages the family’s sense of abandonment, it can serve a crucial preventive role by identifying families at particular risk for serious psychological, social, emotional, and physical sequelae. A history of many losses, mental illness (eg, severe depression or past suicidal behavior), and alcohol or substance abuse, are a few of the issues that may indicate a predisposition to an especially difficult bereavement period. Family relationships that were already fragile or stressed can become severely disrupted or deteriorate further. Extremes of emotion (or lack thereof) in both adults and children that persist over time (eg, consuming rage that envelops the individual and alienates the family/total suppression of any sign of feeling) can be debilitating.

The palliative care team, in conjunction with other community providers, assesses the needs of the bereaved family and assists them directly, or by advocating for and engaging appropriate resources. In most communities there are at least some resources available for the bereaved, including religious institutions, hospice support groups, mental health agencies and providers, and school counselors. A common shortcoming, however, is that services are still geared primarily toward adults and are in short supply for non-English speakers. These reservations notwithstanding, the palliative care team should maintain a current resource list that targets the demographics of their population. Bereaved families are often too drained to initiate contact on their own, and the team can often facilitate referrals for them.

Since most hospitals do not have the resources to support ongoing personal contact from staff, standardized written correspondence (eg, a card to acknowledge a child’s birthday, anniversary of death, or other significant date) can provide a measure of contact and comfort. Care must be taken with such protocols however. In the needs assessment conducted at LPCH,³³ while most families expressed appreciation for condolence cards, several

were ambivalent about receiving further standardized written correspondence. Similarly, it is important to note that at times families desire intense support, while at other times they may wish to disengage from the treating facility and anyone associated with it.

When helping a family through death and bereavement, it is critical that the caregivers keep constant check on their own reactions and beliefs and withhold judgment about the way a family grieves. Furthermore, while many families feel honored and moved at witnessing the professionals’ grief for their child, this compassion must be demonstrated without taking over and superceding the family’s intensity and needs.

Pediatric Palliative Care Reflections of Children and Their Families

The opening two selections are from children who were themselves living the experience of illness (Fig 10). Family members then articulate some of the challenges in facing the threatened, imminent, and now past loss of their child or sibling:

Life is so strange—Karen Josephson

Life is so strange. Sometimes you feel it’s like
a book with chapters to fill, never ending.
Sometimes it’s like a chess game where you have
to make each move so carefully.
Other times it’s like a mystery where each hidden
chamber reveals its secrets.
It is even a war where to live it is to win it.

Karen Beth Josephson⁵ (p. 23)
(died at age 10)

Life and love it up!—Mikaela Clifford

Live and love it up!
Live the best life you can.
Love everyone you love as long as you can.

Mikaela Clifford¹⁰²
(died at age 12)

Stone by Stone—Mariesa Cooper

Stone by stone and brick by brick,
I built a wall huge and thick.
It acts as shelter in the rain
When I can’t block out the pain.
No one to talk to, I felt alone,
I wished I belonged to a different home.
I was afraid to ask what it was all about,
Instead I just tried to tough it out.
They tried to help but I pushed them away,
The truth was I wished they would stay.

Mariesa Cooper (age 15)¹⁰²
sister of Mikaela Clifford



FIG 7. I don't know which side of the rainbow I am on.

I was scared to break down my only protection,
 Would the other side show love and affection?
 People claim that God's the miracle maker,
 So I'm begging you—please—please don't take her.
 I can't think of a day without her face.
 What would I do without her warm embrace?
 I will sit and beg you, plead and plead,
 Don't take my baby sister—she's all I need.
 Just her presence brightens the room,
 You're never left feeling gloom.
 Little by little I chipped at the wall
 And stone by stone it began to fall.
 I can no longer hold this in,
 These are my feelings from deep within.
 Mom, why did you pretend like I wasn't there?
 All I wanted was a little attention and care.
 I know it wasn't your intention to push me aside,
 But that was the start of an emotional roller coaster ride.
 Emotions built and built so high,
 But Daddy told me not to cry.
 All these emotions with nowhere to go,
 So I just held them back and told myself: "No."
 I knew my sister needed care.
 But what about me? It just wasn't fair.
 I'm finally ready to break down this wall,
 It took a while, but I knew it would fall.
 Just vanished, crashed to the ground,
 Not to be thought of or ever found.
 I learned that family's always there,
 No matter what, they will always care.
 Happiness and relief filled me from within,
 A fresh new start, this is where to begin.

*Maria Garcia, mother of infant Emily
 (translated from Spanish)*

For the Mexican people, it is very important that the family is united and close. My family consisted only of my maternal grandmother, my mother, my younger

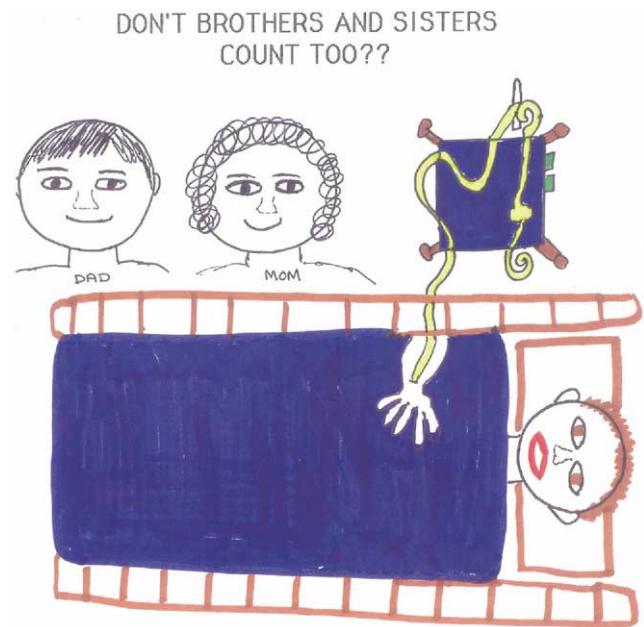


FIG 8. Don't brothers and sisters count too??

brother and my little 4 year-old-daughter. My grandmother became a widow at age 40, and was left with four small children. She was my big example of strength. She told me that what is most important in life is that when something knocks you down to the bottom of the earth, you learn how to get up. After the birth of my first daughter, she became the main reason for me to go forward. My second baby—even she was with us only a short time—she taught me that you have to have strength, courage and fortitude when confronting difficult obstacles that life brings.

My personal advice: There was only one uncomfortable situation at the hospital. There was one doctor in charge of the NICU, and during the change of shift there was no one who could give us information about our babies. I feel that it would be important for parents to be able to receive information about their children during that time. During the weekends, there should be more interpreters and more than one chaplain who speaks Spanish. Mexican people are very close to religion, and at difficult moments, it is very important for them to be able to count on spiritual support.

Nancy and Greg Dougherty, parents of Katie

Our daughter, Katie, died of neuroblastoma on January 3rd, 2004 at the age of ten and a half. Katie had battled the disease for over four years. She underwent surgeries, standard and experimental che-

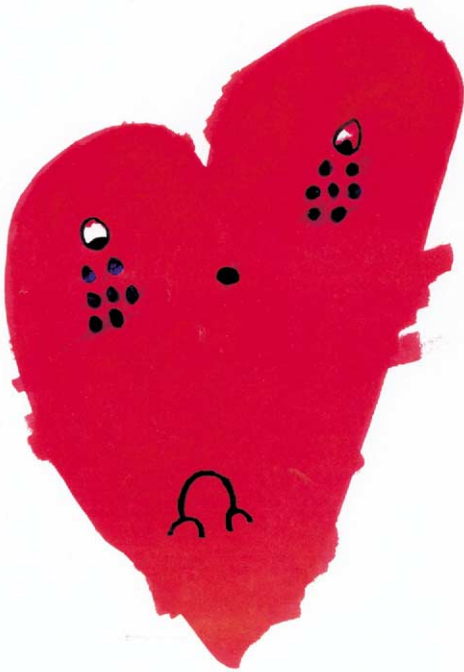


FIG 9. A heart weeping.

motherapy, stem cell transplants, standard and monoclonal antibody targeted radiation and antibody therapy. She participated in Phase I, II and III clinical trials, as well as a pre-Phase I therapy.

From the day of Katie's diagnosis, we knew that her prognosis was not good. Based on the advice that open communication was the best way forward, we kept both Katie and her brother Paul (2 years older) well informed about her condition, treatment options and risks, and the logistics of the chosen course (Fig 11). We did not hide the difficult challenge for beating the cancer. As we look back, it is clear that our openness ensured that both children trusted us and helped us to face the uncertain future as a closely-knit team.

A pivotal example of Katie's sense of control over her own destiny occurred when she read, questioned and signed a children's consent form before entering into a Phase I trial. The dates for the treatment were of particular concern since, along with Paul, Katie was rehearsing her school play (*The Music Man*), the most important thing in her life. After the first round of treatment, her blood counts were coming back more slowly than expected, making the timing of her next cycle uncertain and thus risking a conflict with the week of the performance. In a discussion with her oncologist about the likely revised dates, Katie, who

had not appeared to be listening to the conversation, suddenly piped up: "You know I can stop this treatment at any time. That's what that paper that you had me sign said. So, if the next cycle is going to be during the school play, then I want to drop out of the trial." Needless to say, we did not know whether to laugh or cry. Her doctor looked at her, smiled and said, "Katie, you will not miss the school play. We will schedule your next cycle around your performances." Katie participated triumphantly in all four performances!

Katie maintained this sense of control up until the end of her life. As her cancer progressed, Katie continued to come to the clinic every other day for transfusions—an energy boost that allowed her to enjoy her days at home and even allowed her to attend a holiday party at school. During this period, Katie began to see a palliative care psychologist. We wanted to give her the opportunity to express any fears that she may have been hiding to protect us. When Katie was first asked if she wanted to see the psychologist, she said no. We struck a deal with her that we would go with her and that she did not have to talk unless she wanted to—everything would be up to her. Once in the room (without us present from the start!) Katie began talking. After her first session she told us that she got "lots of energy" from the meeting. In fact, this energy was quite graphic: she reverted back to walking from using a wheelchair. Katie then "referred" her brother Paul to the psychologist.

While we continued to go to the hospital for outpatient transfusions, we began home hospice for pain management (morphine). On Katie's last visit to the hospital at the end of December, she requested a meeting with the palliative care psychologist. Katie drew a color-wheel about how she was feeling that day. She was calm and deliberate, although very weak, as she chose light blue for "tired" and dark blue for "happy." When asked why did not color more, she said that she would have colored more for "happy," but she was too tired to continue. "I am happy with my family." She spoke quietly and smiled.

At this point we told Katie that we understood how tired she was and that she could let go. She understood. Two days later, Katie told us that she did not want to go in for her transfusion. She just wanted to stay home with her family and her dog. Katie died in our home three days later, as she wanted to, in our bed, surrounded by her family.

We often ask ourselves how Katie was able to endure so much and maintain such a positive attitude.



FIG 10. Mikaela and Mariesa.

We have concluded that we were fortunate to have caregivers who got to know us as people and formed a true partnership with us. Most importantly they made Katie feel that *she*—not the cancer—was in charge of her life. While ultimately cancer cheated Katie of her future years, these wonderful people allowed Katie to live a relatively full, albeit short life.

*Paul Dougherty, 13-year-old brother of Katie:
Talk at LPCH Division of Hematology-
Oncology Second Annual Time of
Remembrance*

A year ago, I lost my sister Katie. I am a “chosen sibling.” I made up this term—chosen sibling—to show to other people how I felt about living with a sister with a life-threatening disease. I chose “chosen sibling” as a way of saying we were chosen to do something we did not want to do. We were forced to watch our brothers and sisters go through treatment after treatment. They are amazing—aren’t they? To go through all of that But, we chosen siblings are amazing also. To WATCH our brothers and sisters go through so much—and to worry and be afraid with and for them We should feel proud that we were able to BE THERE for our parents and siblings. Because in a situation like this, family is all that matters Your

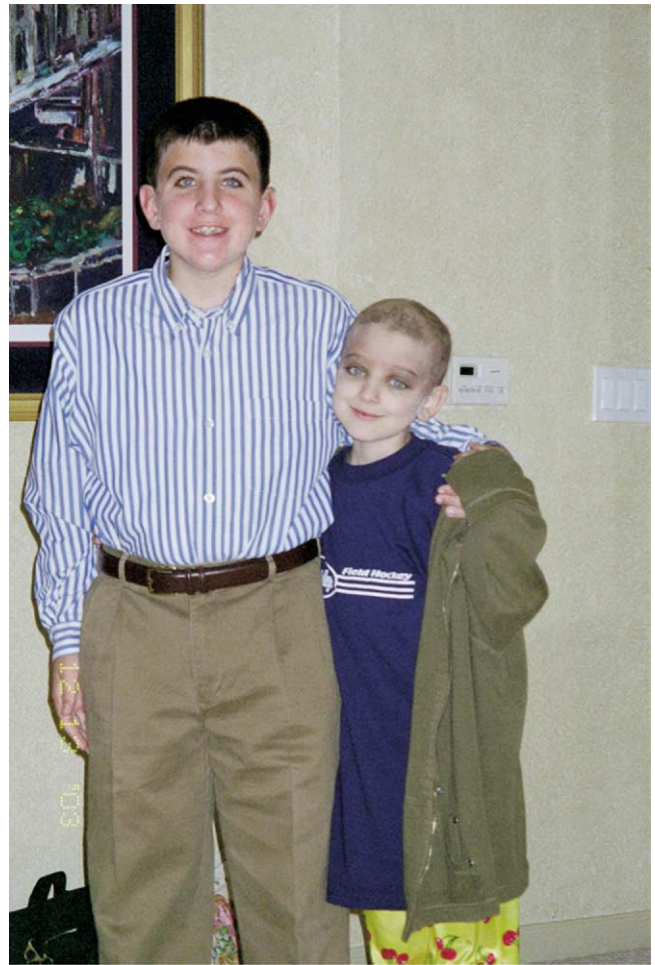


FIG 11. Katie and Paul.

parents and siblings need you as much as you need them.

We should also be happy that our brothers and sisters are now in a better place. It is better for them to be free from treatment and pain than to continue the way they were. You should not feel guilty or blame yourself. We had no way to control events. We should keep our memories and keep going.

The best thing to do is to help others in your situation. Talk to other “chosen siblings” and open up about your experiences. It is not good to clam up. Try talking to an adult in your life whom you trust—parents, a relative, a family friend, a spiritual leader, a teacher, a coach, a counselor. Talking is healing. I learned this by talking to my psychologist, Dr. Sourkes, who understood how I was feeling and has allowed me to voice my experience to other chosen siblings like me.



FIG 12. Matthew and Tess.

Tess Reynolds, mother of Matthew (Fig 12)

There are three things that families want professionals to keep in mind during the palliative care phase of their child's illness:

First, we feel a loss of control. From the time of diagnosis to long after the loss of a child, we families live in an out-of-control world. The progression of the disease is unpredictable, and how our child responds to treatment is unpredictable. We both know that, but you have more experience with illness than we do. Also, the hospital world is new to us, but to you, it's not. Our challenge—to learn your language and protocol—is greater than your challenge to learn ours. So if you have any opportunity to give power and control back to us, even in little ways, please be intentional about doing so. Be patient as you translate medical language into understandable terms. Give us time to think over big and small decisions—that's empowering. Give us choices when you can. Little choices

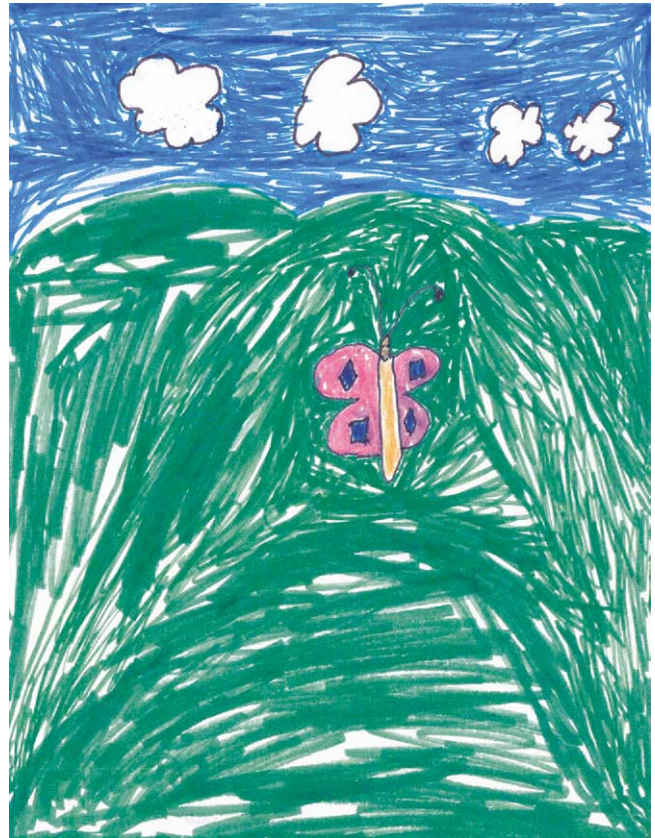


FIG 13. Butterfly—my wings are small.

count for a lot, like checking vitals a half hour later to give our child some extra sleep, or our child getting a shot in the arm versus the leg Anything you can do to put a little bit of control back in our hands will go a long way.

Second, time is precious. Once we face the prospect of our child dying, every moment is precious. All we have is *now*—so honor our time; don't waste it. Don't make us wait any longer than necessary; and if you must be delayed, please tell us to get a cup of coffee for an hour, rather than sit and wait, minute by minute.

Don't make us spend our time telling Team A what we heard from Team B. You may be busy, but in the large scheme of things, you have more time than we do. And whatever time you spend with us, please let it matter. Be really there—present—in the moment—whether good or bad. Look us in the eye. When it's bad-news time, don't run away, hide, or delegate. When it's good-news time, take time to give a hug or a high-five.

Third, don't afraid to be human. We live in a space where we stand vulnerable day after day. A glimpse of your humanness does not diminish our respect for your professional competence. If you are struggling with something, it's better to say, "This is difficult for me," than to put on a professional mask. Tell us that you're sorry for what we're going through. Be real—we know it when you are. And, your human side is what we'll remember many years later.

Toward the Future in Pediatric Palliative Care

The Institute of Medicine Report⁶ put forth recommendations for future research, as well as for direction in three other areas. The need for an ever-present awareness of and sensitivity to multicultural issues underscored all these recommendations, which may be summarized as follows:

- Strengthen research base for effective care

Emphases include appropriate quality-of-life measures; effective symptom management; impact of perinatal death on parents and siblings; impact of sudden death on family and professional caregivers; efficacy of bereavement interventions; models for provision of care; financing alternatives; effective strategies for educating professionals.

- Improve organization and delivery of care

Emphasis is placed on the development of care guidelines and protocols in all pediatric settings, the development of regional information programs and resources in rural areas, and policies and procedures for involving children in decision-making.

- Reform financing of palliative services and hospice care

Vast changes in public and private health coverage: add hospice, change eligibility rules, provide outlier payments, extend coverage for counseling family members and bereavement follow-up.

- Better prepare health professionals

Create educational experiences and curricula that will provide both basic and advanced competence in palliative, end-of-life, and bereavement care.

* * *

What we need is more people who specialize in the impossible.

*Theodore Roethke*¹⁰³
(American poet 1908 to 1963)

My wings are small.

Mikaela, on drawing a vivid butterfly (Fig 13).

* * *

Children's wings may be small, but their horizons and hopes are wide. As they face the extraordinary challenges of illness, it is our challenge to give them—in the words of a 6-year-old child—"aliveness"¹ (p. 167) for however long their life may last. We specialize not only in the *possible*, but in the *essential* to provide the best care for all children. We feel privileged to know these children and families; their resilience and spirit only deepens our own commitment.

Acknowledgments: Thanks to the following individuals who contributed to this article: Sandy Staveski, MSN, Leslie Griffiths, RN, MA, Nancy Baugh MS, RN (nutrition), Christine Rowell MS, PT, Jeanne Kane, MA, Fred Nishioka, PharmD. Thanks also to Belinda Rosales, for all her help in the manuscript preparation, and to Naomi Schapiro MS, CPNP for her wise editing. The Palliative Care team gratefully recognizes the many generous donors to the Lucile Packard Children's Hospital who have made this program possible.

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