

REVIEW ARTICLE

MEDICAL PROGRESS

Pediatric Palliative Care

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EACH YEAR IN THE UNITED STATES, APPROXIMATELY 50,000 CHILDREN DIE and 500,000 children cope with life-threatening conditions. Worldwide these numbers are in the millions.^{1,2} Such children and their families require comprehensive, compassionate, and developmentally appropriate palliative care.

Palliative care is a philosophy of care that evolved from the hospice philosophy to meet the gaps in care for seriously ill and dying patients. The aims of pediatric palliative care should best intersect with the aims of curing and healing, and this approach should be instituted when diagnosis, intervention, and treatment are not limited to a disease process, but rather become instrumental for improving the quality of life, maintaining the dignity, and ameliorating the suffering of seriously ill or dying children in ways that are appropriate to their upbringing, culture, and community.³⁻⁷ Like hospice care, palliative care recognizes that people of all ages die and that caregivers' attention should be focused on relieving patients' pain and suffering. Furthermore, palliative care considers the patient and family as a unique entity whose members require care both before and after death. Palliative care recognizes the role of the physician as one key member of an interdisciplinary team assisting patients and families with the myriad physical, social, psychological, and spiritual needs that come into play when a child has a life-threatening illness.

Palliative care is appropriate for children with a wide range of conditions, even when cure remains a distinct possibility (Table 1).⁸ The American Academy of Pediatrics⁵ has supported concepts of palliative care, stating that "the components of palliative care are offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death." Palliative care should be accessible in any setting, including home, hospital, and school.

 APPROACHES TO AND SUCCESS OF PEDIATRIC PALLIATIVE CARE

Primary care providers should be taught to recognize a child's need for palliative care, to assess the emotional and spiritual needs of the child and family, to facilitate advance care planning, to assess and manage the child's pain and symptoms, to provide bereavement care to the child's family, and to recognize the indications for a referral to a specialist. Essentials of the assessment and planning of pediatric palliative care are presented in Figure 1.^{3-7,9-12} Generalists and specialists alike can and should provide palliative care when needed. At a minimum the team should include a well-trained primary physician, a care coordinator, and in some cases, a bereavement specialist. In addition, support should be available from specialists such as child psychologists and child-life specialists in order to help with the complex psychosocial problems faced by children with life-threatening conditions and their families.

Once a need for palliative care is identified, primary providers have a central role in initiating critical discussions about the trajectory of illness and about advance care plan-

ning. Since a palliative care team may not be immediately available, health care professionals must anticipate and address pain and symptom management while gathering a support team to address all the physical, psychological, and spiritual concerns of the child and family.

ASSESSMENT AND MANAGEMENT OF PAIN AND SYMPTOMS

Timely and skilled management of pain and symptoms should be a cornerstone of each physician's care for children facing life-threatening conditions. In addition, physicians can provide much-needed support by educating the family about what to expect as children move through the trajectory of illness. Health care professionals attending to children facing life-threatening conditions must be willing and able to discuss the possibility of death, the potential for physical and emotional suffering, and the strategies for its prevention and treatment frankly.

Although the importance of providing timely management of pain and symptoms is well recognized, such care is often lacking.¹³ General practitioners who wish to direct the care of children with life-threatening or life-limiting conditions must become familiar with selected pharmacologic and nonpharmacologic treatments for pain, dyspnea, nausea and vomiting, sialorrhea, and seizures (Table 2).^{12,14} Health care providers should consult with pediatric palliative care and pain specialists or local hospice directors with pediatric expertise.

EMOTIONAL AND SPIRITUAL NEEDS

A unique aspect of pediatric palliative care is that the complex experience of life-threatening illness occurs, by the very nature of the child as patient, within the context of growth and development—physical, emotional, social, psychological, and spiritual.¹⁵ Thus, staff working with children who are facing a life-threatening illness and their families must possess fundamental knowledge and expertise in child development and family systems.

Communication with children requires familiarity with their normal emotional and spiritual development (Table 3).^{6,16-21} Effective staff members are emotionally available, candid, and open to children's questions. They encourage feedback and the opportunity for discussion.¹⁹ Physicians also need to support parents and other family members and caregivers. Even as a child's death approaches, parents and caregivers should be encouraged to main-

Table 1. Conditions Appropriate for Pediatric Palliative Care.*
<p>Conditions for which curative treatment is possible but may fail Advanced or progressive cancer or cancer with a poor prognosis Complex and severe congenital or acquired heart disease</p> <p>Conditions requiring intensive long-term treatment aimed at maintaining the quality of life Human immunodeficiency virus infection Cystic fibrosis Severe gastrointestinal disorders or malformations such as gastroschisis Severe epidermolysis bullosa Severe immunodeficiencies Renal failure in cases in which dialysis, transplantation, or both are not available or indicated Chronic or severe respiratory failure Muscular dystrophy</p> <p>Progressive conditions in which treatment is exclusively palliative after diagnosis Progressive metabolic disorders Certain chromosomal abnormalities such as trisomy 13 or trisomy 18 Severe forms of osteogenesis imperfecta</p> <p>Conditions involving severe, nonprogressive disability, causing extreme vulnerability to health complications Severe cerebral palsy with recurrent infection or difficult-to-control symptoms Extreme prematurity Severe neurologic sequelae of infectious disease Hypoxic or anoxic brain injury Holoprosencephaly or other severe brain malformations</p>

* Premature death is likely or expected with many of these conditions.

tain routine, age-appropriate disciplinary habits for the child and to provide consistent and familiar routines.

Working at the child's developmental level mandates the use not only of oral communication, but also of body language and symbolic (expressive) methods of interacting. Commonly used techniques of expressive communication with children include drawing pictures, playing with stuffed animals, writing stories or journals, playing or writing music, and creating rituals. Meeting the child at his or her level of development will encourage the child to express hopes, dreams, fears, and reflections.^{22,23}

How children understand death depends on their level of development (Table 4). A fully mature understanding of death requires integrating the principles of irreversibility, finality and nonfunctionality, universality, and causality. In addition, the concept of death is often influenced by personal, cultural, and experiential factors.^{16,18-21} Research suggests that children understand death as a changed state as early as three years of age, universality by about five to six years of age, and personal mortality by eight to nine years of age.²⁴

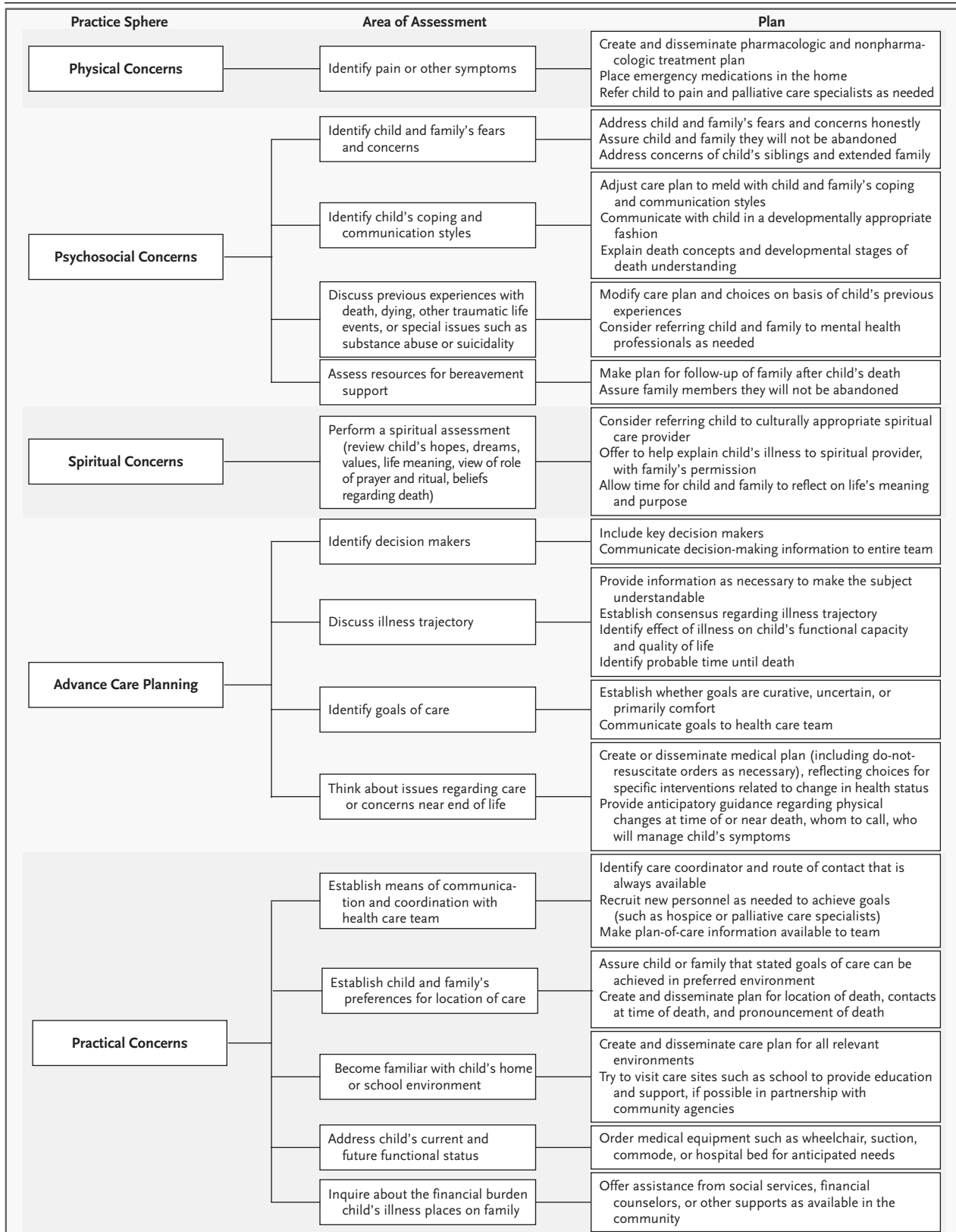


Figure 1. Essential Elements in the Approach to Pediatric Palliative Care.

Spirituality in childhood is also developmentally defined^{25,26} (Table 3). Although spirituality and religiousness may be closely overlapping constructs for adults, children, particularly younger children, may experience spirituality without any personal religious beliefs, values, and practices. Rather, spirituality is more involved in children's approaches to understanding life. Common spiritual concerns include unconditional love, forgiveness, hope, safety and security, and legacy (children, like adults, want to know that their life has made a difference, not only through accomplishments, but also by touching others). Children are also concerned about loneliness (separation from the important elements of their world, such as parents, siblings, school, and pets) and loss of wholeness (being unable to do what they want to do).²⁶

Spiritual assessment centers on understanding the things that are important to the child, as well as the meaning of the child's life to both the child and his or her family and the child's hopes and dreams for the future, realistic or not in the context of disease. Transcendent relationships exist between infants and very young children and their parents and siblings — as exemplified by the connection between a nursing infant and mother. As children develop, transcendent matters such as relationships with God or other higher powers may become important.²⁵

To foster a child's spiritual growth, the physician can be cognizant of and respect the way spirituality changes with age; provide opportunities for the ill child to participate in religious observances at an age-appropriate level; support the growth and maintenance of trusting, secure, and loving relationships; provide support in times of crisis and despair; and allow time for reflection and questioning as part of a child's normal spiritual development. Additional methods for spiritual assessment and management have been outlined elsewhere.^{25,26}

BEREAVEMENT CARE

The process of parent-child attachment begins the moment a child is born, if not before.^{27,28} The loss of a child is one of the most stressful events possible, producing a crisis of meaning in which parents search for cognitive mastery and renewed purpose.²⁹ Grief is a lifelong process; parents typically never fully "get over" the loss of a child but rather learn to adjust and to integrate the loss into their lives. Resumption of everyday function, derivation of pleasure from life, and establishment of new relationships are all signs of healing from grief.

Table 2. Medications Used for Common Symptoms in Pediatric Palliative Care.*

Indication	Medication	Initial Regimen
Pain or dyspnea	Morphine	0.3 mg/kg of body weight orally, SL, or PR every 3–4 hr†
Agitation	Lorazepam	0.05 mg/kg orally, SL, or PR every 4–6 hr
	Haloperidol	0.01–0.02 mg/kg orally, SL, or PR every 8–12 hr
Pruritus	Diphenhydramine	0.5–1.0 mg/kg orally every 6–8 hr
Nausea and vomiting	Prochlorperazine	0.1–0.15 mg/kg orally or PR every 6–8 hr
	Ondansetron	0.15 mg/kg orally or IV every 6–8 hr
Seizures	Diazepam	0.3–0.5 mg/kg PR every 2–4 hr
Secretions	Hyoscyamine‡	0.0625–0.125 mg orally or SL every 4 hr for children 2–12 yr
		0.125–0.25 mg orally or SL every 4 hr for children >12 yr

* SL denotes sublingual, PR per rectum, and IV intravenous.

† Infants younger than six months of age should receive one third to one half of this dose.

‡ The regimen for infants is provided in Taketomo et al.¹⁴

Parents who lose a child are at high risk for complicated grief reactions and may be at increased risk for death from both natural and unnatural causes.³⁰ Complicated grief reactions deviate from the expected for a given society and culture.³¹ These reactions include absent grief, delayed grief, and prolonged or unresolved grief.³² Absent grief refers to the inhibition of typical expressions of grief or denial of the loss or its associated feelings. Delayed grief occurs when there is a substantial time between loss and the onset of the grief reaction, from weeks to years. Prolonged grief is associated with persistent depression, preoccupation with loss, overidentification with and yearning for the deceased, and social inhibition that does not change over time. Bereaved parents appear to be at greatest risk for prolonged grief.³³ Recent research, however, suggests that the differences in levels of psychosocial dysfunction between prolonged grief, classified as pathologic, and normal grief in bereaved parents may be subtle.³²

Children also grieve. In the setting of a life-threatening condition, children may grieve loss of function, interaction, and participation in developmentally appropriate activities of daily living such as play and school. Children nearing the end of life may grieve impending death and suffer with concerns about how survivors will cope. Unfortunately, myths abound regarding children and their capacity to grieve (Table 5). Siblings may also be at risk for a

Table 3. Development of Death Concepts and Spirituality in Children.

Age Range	Characteristics	Predominant Concepts of Death	Spiritual Development	Interventions
0–2 yr	Has sensory and motor relationship with environment Has limited language skills Achieves object permanence May sense that something is wrong	None	Faith reflects trust and hope in others Need for sense of self-worth and love	Provide maximal physical comfort, familiar persons and transitional objects (favorite toys), and consistency Use simple physical communication
>2–6 yr	Uses magical and animistic thinking Is egocentric Thinking is irreversible Engages in symbolic play Developing language skills	Believes death is temporary and reversible, like sleep Does not personalize death Believes death can be caused by thoughts	Faith is magical and imaginative Participation in ritual becomes important Need for courage	Minimize separation from parents Correct perceptions of illness as punishment Evaluate for sense of guilt and assuage if present Use precise language (dying, dead)
>6–12 yr	Has concrete thoughts	Development of adult concepts of death Understands that death can be personal Interested in physiology and details of death	Faith concerns right and wrong May accept external interpretations as the truth Connects ritual with personal identity	Evaluate child's fears of abandonment Be truthful Provide concrete details if requested Support child's efforts to achieve control and mastery Maintain access to peers Allow child to participate in decision making
>12–18 yr	Generality of thinking Reality becomes objective Capable of self-reflection Body image and self-esteem paramount	Explores nonphysical explanations of death	Begins to accept internal interpretations as the truth Evolution of relationship with God or higher power Searches for meaning, purpose, hope, and value of life	Reinforce child's self-esteem Allow child to express strong feelings Allow child privacy Promote child's independence Promote access to peers Be truthful Allow child to participate in decision making

version of complicated grief.³⁴⁻³⁹ Special attention must be given not only to siblings, but also to classmates and peers in the community, since a child's death affects even those outside the obvious circle of family and friends. Bereavement resources are listed in Supplementary Appendix 1 (available with the full text of this article at www.nejm.org).

ADVANCE CARE PLANNING

Advance care planning is the process of helping patients and families make known their wishes about what to do in case of serious or life-threatening problems. Those responsible for advance care planning must become familiar with relevant local, state, and federal laws and practices, such as those regarding do-not-resuscitate orders and standards for sur-

rogate decision making for minors or adults who are not capable of making medical decisions.⁴⁰

Advance care planning is a four-step process. First, the decision makers are identified and included in the process. Second, the patient's or family's understanding of the illness and prognosis is determined and the impending death is described in ways in which the child and the family can understand. Third, on the basis of their understanding of illness and prognosis, the goals of care are established concerning current and future intervention — curative, uncertain, or primarily focused on providing comfort. Finally, shared decisions about the current and future use or abandonment of life-sustaining techniques and aggressive medical interventions, such as mechanical ventilation or artificial hydration, are

Table 4. Elements of Complete Developmental Understanding of Death.

Concept of Death	Questions Suggestive of Incomplete Understanding	Implications of Incomplete Understanding
Irreversibility (dead things will not live again)	How long do you stay dead? When is my (dead pet) coming back? Can I “un-dead” someone? Can you get alive again when you are dead?	Prevents detachment of personal ties, the first step in mourning
Finality or nonfunctionality (all life-defining functions end at death)	What do you do when you are dead? Can you see when you are dead? How do you eat underground? Do dead people get sad?	Preoccupation with the potential for physical suffering of the dead person
Universality (all living things die)	Does everyone die? Do children die? Do I have to die? When will I die?	May view death as punishment for actions or thoughts of child or the dead person May lead to guilt and shame
Causality (realistic understanding of the causes of death)	Why do people die? Do people die because they are bad? Why did my (pet) die? Can I wish someone dead?	May cause excessive guilt

made. As a general rule, decisions made by the patient and his or her family, even if they reflect beliefs and values that differ from those of the primary health care team, should be respected. If these decisions do not seem to fit with the presumed understanding of illness or goals of care, or if the patient or his or her family does not understand the outcomes of these decisions, continued review and reflection and discussion of options are warranted. An ethicist may need to be consulted if the conflict cannot be resolved.

Advance directives — written documents that describe a patient’s or a family’s wishes about health care, designed to capture essential elements of advance care planning — are important in this setting. There are two main types, “instructive” directives and “proxy” directives. An instructive directive is written by someone with decision-making capacity and becomes effective when that capacity is lost. Examples include living wills, Natural Death Act documents, and medical directives. A proxy directive authorizes a specific person or persons to make health care decisions for a patient in the event that the patient loses decision-making capacity. The durable power of attorney for health care is an example of a proxy directive. The 1990 Patient Self-Determination Act passed by Congress set the stage for adults to express their wishes regarding future health care decisions in writing.⁴¹ As discussed below, advance directives written by children under the age of 18 do not currently have legal standing.

BARRIERS TO CARE

The success of medicine in improving survival rates among children with cancer, congenital heart disease, and prematurity has had the unintended consequence of offering false hope to parents that death can always be averted.⁴ In comparison with the 2.3 million deaths of adults each year in the United States, death and life-threatening illnesses in children are relatively rare. Disorders leading to the death of children, with the exception of childhood cancer, encompass many lesser known conditions, including disorders related to short gestation and low birth weight, the sudden infant death syndrome, congenital malformations, deformations, and chromosomal abnormalities.^{2,42} For an adult, particularly one who is elderly or suffering from a long, debilitating illness, death is often an acceptable, and even a desired, outcome⁴³; in contrast, a child’s death remains emotionally difficult, unnatural, and unexpected for families and health care providers alike.

Technology has also contributed to the long-term survival of a new cohort of children with rare disorders and complex medical conditions^{44,45} who in a previous era would have died earlier. Many such children are prone to repeated life-threatening or life-limiting complications. Prognostication for children with such complex problems is extremely challenging, making it difficult for physicians to determine whether or when such children might be dying.

Table 5. Myths and Realities of Childhood Grief.

Topic	Myths	Realities
Do children and adolescents grieve?	Young children do not grieve.	All children grieve.
	Children do not grieve as much as adults.	Children and adults express grief differently but as intensely.
	Children are lucky because they are too young to understand.	Children are vulnerable in their grieving.
	Children should be protected from pain and suffering to maintain their innocence.	Children cannot be protected from death in play, the media, or life experiences.
	Children can resolve grief quickly.	Children's grief has no time limits.
	Children and adolescents understand, experience, and express grief identically.	Children and adolescents are developmentally distinct.
Should children and adolescents be exposed to a loved one who is dying?	Children will be bewildered by being with a loved one who is dying.	Children need to understand and make sense of their experiences in order to help them learn that dying and death are a part of life.
	Children will be traumatized by their last encounters with a dying person.	Children will value having had the opportunity to spend time with a loved one during that person's last days and weeks.
	Happy times that children share with their loved one will be overshadowed by the experience of watching that person die.	Children can learn values through participation in the death of a loved one.
	Children should be protected from seeing a loved one die.	Children may later resent their exclusion; their involvement will assist with grieving.
Should children take part in funerals or other post-death rituals?	Children should not be permitted to take part in such rituals.	Children can benefit in meaningful ways by helping to plan and by attending funerals, including allowing them opportunities for questions and learning from the emotional reactions of adults.
	If children are allowed to participate, their participation should be limited and they should be protected from seeing strong emotional reactions.	Children can benefit from the support of others to help overcome feelings of isolation.
	Adults know better whether or not to allow a child to participate in such rituals after the death.	Difficulties arise either from forcing children to participate against their will or from excluding those wishing to be included.
Are dying children aware of their situation, and how can they be helped?	Dying children <10 years of age are not aware that they are dying.	Dying children know they are dying; adult denial is ineffective in the face of children's emotional perceptiveness.
	Dying children do not experience anxiety because they are unaware that they are dying.	Dying children experience fear, loneliness, and anxiety.
	Dying children have no concerns for themselves or others.	Dying children worry, may try to put their affairs in order, may strive to protect their parents, and fear being forgotten.
	Dying children's questions should not be answered.	Dying children need honest answers and unconditional love and support.

In the setting of remarkable technical advances, families — and some physicians — may view death more as a therapeutic misadventure than as a natural process resulting from disease. Recognition that death is inevitable often lags behind the reality of the medical condition, leading to a treatment approach that is inappropriately aggressive. For example, a child with multiple leukemic relapses may be of-

ferred a third or fourth bone marrow transplantation to attempt to induce a short-term remission or to maintain some quality of life, but with no hope of cure. In such a setting, essential palliative care services might be rejected by the parents, who will continue to view the procedure as curative.

Alternatively, health care providers may assume that a child is dying when, in fact, the likelihood of

recovery to a previous level of function is probable, even though that quality of life may not be perceived to be adequate by the providers. For example, health care providers might question the use of intensive care support for a child in a persistent vegetative state in whom anticonvulsant-induced pancreatitis develops. In these complex situations, palliative care services may be rejected by physicians and parents alike and perceived as tantamount to “giving up on the child,”⁴⁴ even though pediatric palliative care is philosophically committed to helping in such instances, regardless of the outcome.

Complex ethical, legal, and health policy issues affecting children further complicate the timely provision of palliative care.⁴⁵ For example, ethicists increasingly support the concept that adolescents have the ability to participate in medical decision making. Indeed, selected legal decisions about specific cases have supported this viewpoint. However, legislative statutes often do not address treatment decisions or refusals of treatment by adolescents.⁴⁶ In some states, parents’ wishes regarding having a do-not-resuscitate order for their child in the community may not be legally recognized,⁴⁰ despite the fact that ethicists hold that parents are best suited to make decisions in the interest of their children. The primary health care team therefore needs to advocate for the wishes of the child and family in the context of local and state law.

Legal decisions have further encumbered decision making for pediatric health care providers, particularly for those caring for infants. The “Baby Doe” regulations, issued in the mid-1980s to compel the treatment of potentially handicapped infants, were based on the case of an infant with Down’s syndrome and tracheoesophageal fistula whose parents refused to provide consent for surgery to repair the fistula.⁴⁷ Although ultimately overturned by the Supreme Court, these regulations had a substantial impact and steered medical professionals toward the continued use of life-sustaining techniques when these might otherwise have been withdrawn.⁴ Furthermore, amendments to the Child Abuse and Protection Act in 1984⁴⁸ broadened the scope of what is considered child abuse by labeling the withholding of medically indicated treatment for an infant with a life-threatening condition as a component of medical neglect. Resulting regulations stipulated that handicapped infants must always receive life-sustaining treatment except in cases of irreversible coma or treatments that would be inhumane or futile or would prolong the

dying process.⁴ Although the U.S. government has yet to intervene on behalf of an allegedly medically neglected infant, these court decisions have made neonatologists apprehensive about withdrawing or withholding life-sustaining therapies for dying infants.⁴⁹

Many patients — adult and pediatric — who require palliative care services do not meet eligibility criteria for community-based hospice services. The Medicare Hospice Benefit, created by Congress in 1982, provides a per diem reimbursement for care of patients determined to have no longer than six months left to live and for whom the goal of care is palliative rather than curative.⁵⁰ Most hospice care is provided in the home, yet the majority of infants and children die in hospitals.⁵¹ Children under 17 years of age make up only 0.4 percent of all hospice admissions.⁵² Thus, few hospice providers admit a sufficient number of children to achieve or maintain expertise in pediatric care.^{3,4,9,53} Furthermore, children with complex medical conditions⁵⁴ may have health care needs, such as a requirement for parenteral nutrition, transfusion, assisted ventilation, or in-home “shift” or “block” nursing, that are not reimbursable under existing systems of hospice insurance.

Fragmented care adversely affects children with complex medical conditions. For example, a child with severe neurologic deficits who has stridor and reactive airway disease, spasticity, a feeding tube, scoliosis, and seizures may be served by a primary care provider, orthopedic surgeon, pulmonologist, otolaryngologist, gastroenterologist, nutritionist, neurologist, multiple physical and occupational therapists and physical medicine and rehabilitation specialists, a provider of durable medical equipment, a home-care company, a tutor, and representatives from a faith-based community. Facilitating and coordinating care among these many providers are daunting and underfinanced tasks in pediatric palliative care.

The assessment and management of symptoms and suffering in children are difficult.^{55,56} Few reliable, valid, and developmentally appropriate methods are available for measuring the suffering and quality of life of children with life-threatening illness, and few researchers and research dollars are devoted to improving the state of symptom control in children. In a retrospective, single-institution study of the parents of children who died of cancer, Wolfe et al. noted that most symptoms were reported more frequently by parents than by physicians,

the majority of children suffered “a lot” or “a great deal,” and the treatment of symptoms was often ineffective,¹³ findings indicating a scope of distressing symptoms similar to those seen in adult patients with cancer.⁵⁷

Substantial research strides have been made in adult palliative medicine in the past five years, creating measures with which to gauge the quality and effect of palliative care services. These include an understanding of the definitions of a “good death” and of the quality of life from the perspective of adult patients and an identification of treatment preferences and factors important in advance care planning. Knowledge has also been gained about the beliefs, attitudes, and feelings of professional staff members; the burdens that patients with chronic illnesses place on caregivers; and the assessment and management of pain and symptoms.⁵⁸⁻⁶⁹ Similar studies have been rare among children with life-threatening illnesses,^{70,71} and a “good death” in a child remains undefined.⁷² Multicenter studies would be required to determine the best practices, to establish appropriate outcome measures, to assess the current management of emotional and spiritual distress, and to learn whether current ap-

proaches to and therapies for bereaved parents and children are effective.^{73,74}

CONCLUSIONS

A wealth of new information is available for the generalist and the specialist with an interest in pediatric palliative care (see Supplementary Appendix 1). In the past 10 years a range of palliative care clinical programs has been developed in hospitals, hospices, home care programs, and long-term care facilities to help fill the gap between traditional hospital care and community-based hospice care. Although it represents an ideal, the presence of a designated pediatric palliative care team in all health care facilities that serve life-threatened children is currently a luxury. New efforts are under way to expand pediatric palliative care services, led by the Palliative Care Leadership Centers/Center to Advance Palliative Care.⁷⁵

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