Palliative Care for Children

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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time to rest and renew, whether for hours or days, on a schedule, or intermittently as needed. Families may benefit from the provision of respite care throughout a child’s illness, not only near the end. Appropriate pediatric respite care is often lacking, but is considered by many families to be essential for their continued integrity and ability to care for the ill child, siblings, and themselves. Ideally, the patient’s pediatrician, family physician, pediatric subspecialist, or surgeon will offer to continue to care for the child, while making a timely referral to palliative and hospice care. Palliative care programs should assist the child’s usual medical caregivers in maintaining an ongoing role in the child’s care.

Support for the Caregivers
Health care professionals must be supported by the palliative care team, their colleagues, and institutions in dealing with the child’s dying process and death. Institutional support may include paid funeral leave, routine counseling with a trained peer or psychologist, and regularly scheduled remembrance ceremonies or other interventions such as inviting bereaved families to return and celebrate with staff the deceased child’s life.

Improved Professional and Social Support for Pediatric Palliative Care
Regulatory, financial, and educational barriers often bar families from access to pediatric palliative care services. Professional and public education may foster awareness of the need for, and value of, pediatric palliative care and lead to efforts to remove bureaucratic and economic obstacles to its availability.

Continued Improvement of Pediatric Palliative Care Through Research and Education
Clinical research concerning the effectiveness and benefits of pediatric palliative care interventions and models of service provision should be promoted. In addition, information about pediatric palliative care that is already available must be effectively disseminated and incorporated into education and practice.

AN INTEGRATED MODEL OF PALLIATIVE AND CURATIVE TREATMENT
The AAP supports an integrated model of palliative care “in which the components of palliative care are offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death.” It is difficult to determine which children may benefit from palliative care. If palliative care is reserved for children who are dying or have a terminal condition, other patients who may benefit from these services may not receive them. Time of death is often difficult to predict. If the nearness of death is used to determine if children receive palliative care, some children may die without the benefits of individualized family-centered palliative care. With a broader definition that includes children living with a life-threatening condition, all children who need palliative care may benefit. In addition, aspects of an integrated palliative care approach, including symptom management and counseling, may prove beneficial when provided early in the course of a child’s illness. Curative treatments seek to reverse the disease process, whereas palliative treatments focus on relieving symptoms, regardless of their impact on the underlying disease process. Rigid distinctions between curative, life-prolonging, and palliative interventions may hinder the appropriate provision of palliative care to children living with a terminal condition. Physicians and family members may exhaust all curative options before they consider palliative care, which delays the timely introduction of palliative care or referral to palliative care specialists. Finally, it may be difficult to define individual therapies as either curative or palliative. For example, mechanical ventilation often is viewed as a life-prolonging or curative therapy that should be forgone with palliative care. However, such support, especially noninvasive forms of positive pressure ventilation, may provide symptomatic relief from dyspnea and significantly improve a child’s quality of life.

Moreover, the assumption that there is no place for palliative care until all curative options have been exhausted may interfere with an early discussion of palliative issues, including limitations of unduly burdensome interventions at the end of life. Parents and children may infer that a discussion of issues such as do not resuscitate orders or comfort care is equivalent to “giving up.” Such inferences may inhibit family members from voicing fears and concerns about the burdens of life-prolonging interventions and the dying process. Communication with patients and families about these concerns must be done with respect and empathy. An explanation of the usefulness of specific therapies, such as cardiopulmonary resuscitation, and a discussion of the value of advance directives to ensure that treatments that have become burdensome are not used, can be comforting to families. The ability of health care professionals to communicate difficult messages well can be learned through directed education and practice.

DEVELOPING A PALLIATIVE CARE PLAN
As no one person can provide all the necessary support for the child and family, palliative care is best provided using an integrated interdisciplinary approach. The provision of palliative care for children involves a partnership between the child, family, parents’ employer(s), teachers, school staff, and health care professionals, including nurses, chaplains, bereavement counselors, social workers, primary care physicians, subspecialty physicians, and consultants. Physical, emotional, psychosocial, and spiritual/existential domains of distress must be addressed. The child should participate to the fullest extent possible, given his or her illness experience, developmental capacities, and level of consciousness. Regardless of the prognosis, respect for the child requires that he or she be given a developmentally appropriate description of the condition along
with the expected burdens and benefits of available management options, while soliciting and listening to the child’s preferences. For example, burdens may include time away from home and friends; benefits may include participation in research studies based on an altruistic motive. The discussion should focus on what interventions, from the child’s and family’s perspective, will be of the most benefit.

Each available diagnostic or therapeutic intervention needs to be considered within the context of the goals and expectations of the child and family. The decision to forgo certain treatments means that only those selected interventions are withheld or withdrawn. As the goals of therapy change with the progression of the child’s condition or disease, the desirability of some interventions may change. Early interdisciplinary discussion and planning facilitates the smooth integration of these changes. The relief of pain and anxiety is an essential aspect of palliative care, and should be addressed throughout the course of illness. In some instances, pain relief may free a child to participate more fully in his or her final days, weeks, or months of life. Openness to the day-to-day experience of the child and flexibility in considering all options that may palliate distressing symptoms and conditions are essential when developing a treatment plan. The goal is to add life to the child’s years, not simply years to the child’s life.

WORKING WITH PARENTS OF DYING CHILDREN

While acknowledging uncertainty, a pediatrician needs to provide a realistic appraisal of prognosis and the range of time in which death is likely to occur. Pediatricians should support parental expression of the disappointment, anger, grief, and suffering associated with the child’s illness. Acknowledging grief is often the first step toward facing the reality of the child’s illness. Such acceptance may help parents focus on the quality of the child’s remaining life. Most importantly, the pediatrician needs to reassure the parents and child of the continued involvement and support of caring, skilled clinicians throughout the child’s life, as well as after death. Fear of abandonment and isolation, especially during a child’s long illness, is a major concern to chronically ill or dying children and their families.

The place where death occurs, whether in an intensive care unit, another area of the hospital, another institution, or at home, may depend on such factors as the wishes of the child and family, the physical layout and visitation policies of the alternative sites, the desire and ability of staff to remain involved, and the availability of other caregivers such as bereavement counselors and clinicians with palliative care expertise. Whether death is anticipated or unexpected, pediatricians are expected to help support parental grief and guilt as parents struggle to cope with their fundamentally incomprehensible loss. The family must have the opportunity to carry out important family, religious, and/or cultural rituals and to hold the child before and after death. Members of the extended family, friends, primary care physicians, and religious advisors are to be included, if the family chooses. These individuals can support the family and each other during this time of crisis and in bereavement. A handwritten note of sympathy from the pediatrician or attendance at the funeral can be healing for the family and the physician. In addition, an opportunity for either organ and/or tissue donation when feasible, and an explanatory meeting with the pediatrician to share the results of a limited or full autopsy, may provide some comfort for a grieving family.

The death of a child who has been chronically ill presents added challenges. Parents grieve the loss of the expected normal child from the time of diagnosis of a condition likely to result in disability and childhood death. Often, these parents may find it difficult to accept the reality of impending death, perhaps because previous predictions proved inaccurate. For some parents, continued hope for cure, no matter how unlikely, may be an important coping mechanism or may conform with deeply held religious or cultural beliefs.

WORKING WITH CHILDREN

As many children with chronic, life-shortening illnesses are now living into adolescence and young adulthood, the pediatrician needs to acknowledge the child’s own recognition of the likelihood of premature death, to help the child communicate his or her wishes, and to plan for the child’s death. The pediatrician should assist parents in understanding and supporting the siblings of the ill child, all of whom are affected by the child’s condition and eventual death. Parents are to be supported in attending to the needs of the ill child and siblings while acknowledging the sadness that results from life-threatening illness. The child should be reassured that he or she has done nothing wrong and is not responsible for his or her own illness or that of a sibling. Children should be encouraged to talk about feelings of anger, sadness, fear, isolation, and guilt, or to express themselves through art or music therapy. Pediatricians should provide families with developmentally appropriate guidance about these difficult communications, encourage parents of older children and adolescents to talk together as a family about their feelings, and encourage the sharing of memories to facilitate bereavement and healing. Families may benefit from the pediatrician or another member of the palliative care team participating in such family discussions. In these tragic situations, it is also helpful for the primary care pediatrician to work with the schools and other youth organizations to assist other children affected by the death of the child.

The pediatrician and the child’s parents may consider the following factors when discussing death with a child: the disease experience and developmental level of the child; the child’s understanding of and prior experience with death; the family’s religious and cultural beliefs about death; the child’s usual patterns of coping with pain and sadness; and the expected circumstances of death.
The AAP does not support the practice of physician-assisted suicide or euthanasia for children.

**BARRIERS TO THE PROVISION OF PEDIATRIC PALLIATIVE CARE**

Primary care pediatricians may be unfamiliar or uncomfortable with counseling or managing a child and family in palliative care, given the infrequency of death in most practices. Thus, early consultation with pediatric hospice or palliative care professionals may be useful. Nevertheless, pediatricians who have established relationships with a child and family may assist in evaluating proposed interventions, help monitor the health and well-being of the siblings and family, and attend to the sometimes subtle and prolonged effects of grief on the family after the palliative care or hospice program is no longer involved.

Unfortunately, the majority of children who die have not had the benefit of palliative care services. A major factor impeding pediatric palliative care is that the federal Medicare model was used to create most state Medicaid hospice benefits. The Medicare model of hospice care was designed for adult patients with cancer, restricting admission to patients with a life expectancy of 6 months or less. This stipulation restricts the availability of hospice services to children, given the difficulty in predicting length of survival for many of the childhood diseases that result in premature death. Some hospice programs may require that patients and families agree to forgo life-prolonging or curative treatments and perhaps authorize a do not resuscitate order as a requirement for admission. Such requirements ignore the fact that many families accept the concept of hospice care only after a counseling process that is available within a hospice or palliative care program.

In addition, children living with a life-threatening or terminal condition may be receiving therapies that improve their quality of life, but are not adequately reimbursed through Medicaid hospice benefits. Treatment that generally is not reimbursed, for example, includes the use of newer, more expensive antibiotics for children with cystic fibrosis, long-term ventilator therapy for children with neuromuscular disorders, or surgical interventions that may palliate the child’s symptoms. Reimbursement and regulatory policies may also preclude appropriate hospitalizations for children with life-threatening conditions. Moreover, families qualifying for Medicaid hospice benefits may lose other state-provided benefits, including dietary supplements and, more importantly, skilled home nursing care. Finally, health benefits from private insurance companies often mimic those from Medicare, and most do not have specific provisions in place for children.

Although hospice personnel are better equipped than most health care professionals to address issues surrounding terminal conditions, many hospice programs lack pediatric expertise and thus deprive chil-
children and their families of the benefits of palliative care. Limited access to pediatric-specific palliative care and hospice services deprives children of knowledgeable health care personnel for home-based pain and symptom management. Many families may have to choose between life-prolonging or palliative care, and between pediatric or nonpediatric health care professionals, rather than have the opportunity to develop an individualized treatment plan that accounts for the specific needs of the child and family. As a result, the child living with a life-threatening or terminal condition may suffer an unnecessarily poor quality of life, leaving surviving family members with an excessively difficult bereavement.

**MINIMUM STANDARDS FOR PEDIATRIC PALLIATIVE CARE**

Excellence in pediatric palliative care is essential for hospitals and other facilities caring for children. Program development in pediatric palliative care, along with community outreach and public education, must be a priority of tertiary care centers serving children.

Minimum standards of pediatric palliative care must include a mechanism to ensure a seamless transition between settings, including at least 1 consistent caregiver, the availability of expert pediatric palliative care assistance 24 hours a day, 365 days a year, and the availability of an interdisciplinary care team with sufficient expertise to address the physical, psychosocial, emotional, and spiritual needs of the child and family. At the minimum, this team will include a physician, nurse, social worker, spiritual advisor, and child life therapist.

Although palliative care services may not be necessary for all families, the full range of clinical and educational resources must be made available. In addition, comprehensive palliative care cannot be accomplished without a designated care coordinator who can maintain continuity and ensure the care provided is consistent with the child’s and family’s goals despite the intermittent care and high staff turnover associated with tertiary care centers. The coordinator can ensure that the plan of care is coordinated with community care professionals to ensure a realistically achievable plan. Tertiary centers must provide community caregivers with explicit instruction in the care of the child, and appropriate pediatric palliative care consultation must be available 24 hours a day. Creative ways of coordinating care between the tertiary center and the community may involve individualized video conferencing or other forms of electronic communication. Respite for family caregivers and home nursing care are essential to maintain the integrity of families and the safety and well-being of the ill child. Finally, bereavement support must be available to the family, caregivers, and others affected by the death of a child, for as long as necessary. These essential services must be reimbursed equitably. The early inclusion of insurance case managers on the palliative care team may assist in accomplishing some of these goals.

Nursing, medical, pastoral, and social work curricula must include interdisciplinary management of childhood life-threatening conditions. Practical exercises involving interdisciplinary education, including hospice visits, may best achieve this goal. In addition, attending to the needs of children who experience the death of a significant adult must be addressed. The requirement to achieve competency in these areas must be reinforced by adding questions on palliative care to professional certification examinations. The needs of the medical caregivers who provide pediatric palliative care must be recognized and actively addressed to allow them to continue to provide this rewarding but emotionally draining care.

**RECOMMENDATIONS**

1. Palliative care and respite programs need to be developed and widely available to provide intensive symptom management and promote the welfare of children living with life-threatening or terminal conditions.

2. At diagnosis of a life-threatening or terminal condition, it is important to offer an integrated model of palliative care that continues throughout the course of illness, regardless of the outcome.

3. Changes in the regulation and reimbursement of palliative care and hospice services are necessary to improve access for children and families in need of these services. Modifications in current regulations should include 1) broader eligibility criteria concerning the length of expected survival; 2) the allowance of concurrent life-prolonging and palliative care; and 3) the provision of respite care and other therapies beyond those allowed by a narrow definition of “medically indicated.” Adequate reimbursement should accompany these regulatory changes.

4. All general and subspecialty pediatricians, family physicians, pain specialists, and pediatric surgeons need to become familiar and comfortable with the provision of palliative care to children. Residency, fellowship training, and continuing education programs should include topics such as palliative medicine, communication skills, grief and loss, managing prognostic uncertainty, and decisions to forgo life-sustaining medical treatment, spiritual dimensions of life and illness, and alternative medicine.33,37,38 Pediatric board and subboard certifying examinations should include questions on palliative care.

5. An increase in support for research into effective pediatric palliative care programming, regulation and reimbursement, pain and symptom management, and grief and bereavement counseling is necessary. The pharmaceutical industry must provide labeling information about symptom-relieving medications in the pediatric population and provide suitable formulations for use by children.

6. The practice of physician-assisted suicide or euthanasia for children should not be supported.

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