



## POLICY STATEMENT

# Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations

## abstract

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Pediatric palliative care and pediatric hospice care (PPC-PHC) are often essential aspects of medical care for patients who have life-threatening conditions or need end-of-life care. PPC-PHC aims to relieve suffering, improve quality of life, facilitate informed decision-making, and assist in care coordination between clinicians and across sites of care. Core commitments of PPC-PHC include being patient centered and family engaged; respecting and partnering with patients and families; pursuing care that is high quality, readily accessible, and equitable; providing care across the age spectrum and life span, integrated into the continuum of care; ensuring that all clinicians can provide basic palliative care and consult PPC-PHC specialists in a timely manner; and improving care through research and quality improvement efforts. PPC-PHC guidelines and recommendations include ensuring that all large health care organizations serving children with life-threatening conditions have dedicated interdisciplinary PPC-PHC teams, which should develop collaborative relationships between hospital- and community-based teams; that PPC-PHC be provided as integrated multimodal care and practiced as a cornerstone of patient safety and quality for patients with life-threatening conditions; that PPC-PHC teams should facilitate clear, compassionate, and forthright discussions about medical issues and the goals of care and support families, siblings, and health care staff; that PPC-PHC be part of all pediatric education and training curricula, be an active area of research and quality improvement, and exemplify the highest ethical standards; and that PPC-PHC services be supported by financial and regulatory arrangements to ensure access to high-quality PPC-PHC by all patients with life-threatening and life-shortening diseases. *Pediatrics* 2013;132:966–972

## INTRODUCTION

Over the past two decades, pediatric palliative care has emerged as an established field of medical expertise and practice.<sup>1–3</sup> Recognized in 2006 by the American Board of Medical Specialties, hospice and palliative medicine is the field of medical expertise that seeks to improve quality of life and reduce various forms of distress for patients and their families in the face of serious life-threatening or inevitably life-shortening conditions or when end-of-life care or bereavement services are needed. Pediatric palliative care addresses the needs of infants, children, adolescents, and young adults (subsequently referred to

## SECTION ON HOSPICE AND PALLIATIVE MEDICINE AND COMMITTEE ON HOSPITAL CARE

### KEY WORDS

pediatric, fetus, newborn, infant, child, adolescent, young adult, palliative care, hospice care

### ABBREVIATIONS

AAP—American Academy of Pediatrics

PPC-PHC—pediatric palliative care and pediatric hospice care

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[www.pediatrics.org/cgi/doi/10.1542/peds.2013-2731](http://www.pediatrics.org/cgi/doi/10.1542/peds.2013-2731)

doi:10.1542/peds.2013-2731

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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collectively as “children”) with these conditions and the needs of their families, providing treatments that aim to (1) relieve suffering across multiple realms, including the physical (eg, pain or dyspnea), psychological (depression, anxiety, or sense of guilt), social (isolation), practical (home-based services or financial stress), and existential or spiritual (why is this happening?); (2) improve the child’s quality and enjoyment of life while helping families adapt and function during the illness and through bereavement; (3) facilitate informed decision-making by patients, families, and health care professionals; and (4) assist with ongoing coordination of care among clinicians and across various sites of care.<sup>4–7</sup>

Hospice care is a particular form of palliative care, delivered in the United States by licensed hospice agencies. As mandated by federal regulation, these agencies provide a bundle of services, including nursing, physician, psychosocial, and spiritual services; medications; durable medical equipment; and a range of diagnostic tests and therapeutic interventions. These services are financed by an all-inclusive per-diem rate and most often are provided in the home setting for pediatric patients. As with adult patients, these services also can be provided in dedicated inpatient hospice beds or units within hospitals, self-standing hospice centers, and long-term care facilities. Also by regulation, hospice care is provided by an interdisciplinary team including physicians, nurses, chaplains, social workers, home health aides, therapists, volunteers, and bereavement counselors. At present, hospice is a widely available palliative care option in the United States for adults but often is not a viable option for pediatric patients, for two principal reasons. First, few hospices currently have the capacity to care for infants,

children, and adolescents, because pediatric treatment plans are sometimes too unfamiliar, complex, and costly for traditional hospice programs. Second, insurance coverage is often restricted or limited. Following the mandates specified in the Medicare hospice benefit, most public and private payers specify that to qualify for hospice services, the patient must have a life expectancy of 6 months or less if the disease follows its expected course, and enrolling in hospice typically entails curtailment of other health care services. However, the Patient Protection and Affordable Care Act (2010 [Pub L No. 111-148]) specifies that children enrolled in Medicaid or the Children’s Health Insurance Program can concurrently receive both hospice services and life-extending disease-directed therapy.<sup>8</sup> Although individual physician consultation is a billable service, pediatric palliative care services per se, particularly those performed by nonclinician members of the interdisciplinary team, are typically not covered by either public or private insurance payers except for small pilot programs.<sup>9</sup>

Pediatric palliative care and pediatric hospice care (PPC-PHC) teams collaborate to serve the needs of families and children living with life-threatening conditions. These services are more extensive and of much longer duration than end-of-life services, because PPC-PHC teams are often appropriately used by most patients for months to years.<sup>10</sup>

The American Academy of Pediatrics (AAP) continues to advocate for the development, adoption, and adherence to clinical policies and guidelines that promote the welfare of children living with life-threatening conditions and their families, with goals including the provision of accessible, equitable, and effective support for cure-directed, life-prolonging, and palliative care. While incorporating advances in this field and

acknowledging the need for additional clinical and health service research, this statement reflects current expert consensus as it reaffirms the principles of the original AAP statement published in 2000.<sup>11</sup>

## **PALLIATIVE CARE AND HOSPICE CARE COMMITMENTS**

The following core commitments serve as the foundation for an integrated model of PPC-PHC.

### **Patient Centered and Family Engaged**

PPC-PHC is centered on the child, with a constant commitment to providing the best possible care for that child in a manner that fully engages, respects, and partners with the patient’s family.<sup>12</sup>

### **Respect and Partnering**

Respect is manifested by partnering with the child and family, soliciting their understanding of the child’s medical condition, eliciting and clarifying their values and preferences, and formulating a plan of care based on those values and preferences in partnership with the patient and family. The child should participate to the fullest extent possible, given his or her preferences, cultural and spiritual tradition, illness experience, developmental capacity, and level of consciousness. Consistent with this principle of respect, information about palliative care should be readily available, and policies should allow patients and parents to initiate referral to a pediatric palliative care program.

### **Quality, Access, and Equity**

PPC-PHC seeks to provide equal access for all patients and families to high-quality and effective interventions to ameliorate pain and other distressing physical and psychological symptoms as well as social, practical, and spiritual sources of distress.<sup>13</sup> PPC-PHC programs should adhere to established

PPC-PHC quality metrics and guidelines.<sup>14</sup>

In contrast to quality metrics being monitored in adult hospice and palliative medicine, the place where death occurs is not an appropriate quality of care indicator for PPC-PHC.<sup>15</sup> The location may depend on such factors as the wishes of the child and family, the physical layout and geographic location of the home, and for children who reside in a facility, the policies of the facility and the desire and ability of staff to provide the necessary care. For these reasons, admission (or readmission) to the hospital of a patient for symptom management or end-of-life care may be warranted.

### **Care Across Age Spectrum and Life Span**

The PPC-PHC team is committed to caring for patients with conditions and illnesses that develop prenatally or during infancy, childhood, or adolescence, even when these patients age into adulthood (which is occurring for an increasing number of patients with a wide range of serious life-threatening conditions). Ideally, this commitment should be honored by promoting timely transitioning of care to comprehensive, high-quality adult-oriented services for people with pediatric-specialty conditions, and these services should be developed and supported so that transitions can occur smoothly and safely.<sup>16</sup> When such transitions cannot be guaranteed, however, the commitment to high-quality care remains for the pediatric providers. Furthermore, when a patient dies, the commitment to the family continues during the period of bereavement.

### **Integration Into the Continuum of Care**

For all patients, high-quality PPC-PHC should routinely prevent and treat distressing symptoms, such as pain,

nausea, or anxiety, and seek to maximize quality of life, which may entail various interventions depending on the patient's specific goals. Dedicated specialty PPC-PHC teams should be consulted for advanced clinical treatments and complicated decision-making and for social and spiritual needs beyond what the primary care team can provide. These consultations can occur throughout a child's illness experience, including at initial diagnosis, when the goals of care are focused on cure. PPC-PHC should be integrated throughout the illness course, providing interventions to support the goals of care, which often shift over time. After initiating a PPC-PHC consultation, the patient's medical home and all providers (including primary pediatricians or family medicine physicians, pediatric specialists, and surgeons) should remain fully engaged in the well-coordinated care for the child.

### **Universal Preparedness and Consultation**

All physicians should be trained in basic approaches to prevent, assess, and manage symptoms and to communicate in a clear, caring, and collaborative manner with patients and families. All physicians should also be able to recognize when and how to consult with PPC-PHC specialists and how to inform patients and families of the role PPC-PHC specialists play to ensure that patient care is consistent with best practices.

### **Research and Continuous Improvement**

PPC-PHC should vigorously promote and pursue rigorous research and quality improvement projects in all aspects of interdisciplinary care, including evaluation of specific pharmacologic and nonpharmacologic interventions to alleviate symptoms; medical and

psychosocial interventions to improve quality of decision-making and quality of life for patients and family members; various modes of education and training to improve clinicians' knowledge, attitudes, skills, and behaviors; and different program or service delivery models to improve access, outcomes, and cost-effectiveness.<sup>17–21</sup>

## **GUIDELINES AND RECOMMENDATIONS**

The following 12 guidelines and recommendations are based on a combination of published observational studies, expert opinion, and consensus statements.

### **1. Composition and Capacity of PPC-PHC Specialty Teams**

All hospitals and large health care organizations that frequently provide care to children with life-threatening conditions and routinely provide end-of-life care should have dedicated interdisciplinary specialty PPC-PHC teams. These teams should support decision-making, provide timely and effective interventions to minimize suffering while maximizing quality of life, and manage and coordinate the logistics of care to provide seamless transitions between settings and maintain the highest possible quality of care. Teams should have sufficient collective expertise to address the physical, psychosocial, emotional, practical, and spiritual needs of the child and family. Although programs often start with only a few team members, mature teams should include physicians, nurses, social workers, case managers, spiritual care providers, bereavement specialists, and child life specialists. To ensure quality and safety, teams must have an adequate number of dedicated staff, ideally trained in PPC-PHC, be paid specifically to provide pediatric palliative care, and be available for consultation anytime. These

consultative activities should bridge the physical locations of patients, from their homes or schools to the hospital and, potentially, to other partnering facilities.

## 2. Relationships With Hospices and Hospice Pediatric Standards

PPC-PHC teams in geographic regions should proactively develop collaborative relationships.<sup>22,23</sup> Despite steady growth in the hospice industry, recent evidence indicates that hospices willing to care for children are decreasing in number.<sup>24</sup> All hospices are encouraged to provide care to children to maintain a core level of competency; hospices caring for children should adhere to the National Hospice and Palliative Care Organization Standards of Practice for Pediatric Palliative Care and Hospice.<sup>14,25</sup>

## 3. Collaborative Integrated Multimodal Care

PPC-PHC should be provided as collaborative integrated multimodal care, including cure-seeking, life-prolonging (when in the child's best interest), comfort-enhancing, and quality-of-life enriching modes of care, along with psychological, spiritual, and social support for the family.<sup>26</sup> Collaboration is essential; patient, parents, other involved extended family members and friends, schools, parental employers, and all involved members of the primary and specialty health care team must collaborate to meet the needs of patients most effectively. The medical homes and pediatricians who provide primary and specialty care to children with life-threatening conditions remain invaluable, must advocate for and involve interdisciplinary PPC-PHC in the care of these patients and their families, and, for their patients, may become active members of the interdisciplinary palliative care team.

## 4. Patient Care Safety and Quality

PPC-PHC is a cornerstone of patient care safety and quality for patients with life-threatening conditions.<sup>15,27</sup> Consultation with PPC-PHC professionals should be considered for complicated pain and other symptom management or when difficult decision-making and communication issues arise. Once consulted, PPC-PHC teams should review all of a child's diagnoses and, if any are uncertain, seek to confirm them. PPC-PHC teams should assist primary and specialty care teams in providing a realistic appraisal of prognosis, including anticipatory guidance about the likelihood of future symptoms, impairments, and mortality, and the timeframe during which these outcomes are likely to occur. Distressing symptoms should be managed promptly and effectively to minimize suffering and avoid unintentional consequences of polypharmacy. Symptom management should be augmented by other services and therapies to maximize the child's quality of life.<sup>28</sup> Bereavement care should be provided for anticipatory grief and continue after the death of a child throughout the bereavement period (which often lasts longer than a year). PPC-PHC teams should conduct ongoing quality improvement reviews and projects aiming to improve patient and family experiences and outcomes.

## 5. Communication and Decision Support

PPC-PHC clinicians should facilitate clear, compassionate, and forthright discussions with patients and families about therapeutic goals and concerns, the benefits and burdens of specific therapies, and the value of advance care planning. At a minimum, goals of care and treatment choices should be revisited whenever requested by the patient or family, with every hospitalization or with any significant change

in treatment course or prognosis, and at least annually for children with complex chronic conditions. Any changes in goals of care or treatment plan should be communicated to all involved members of the child's care team and medical home. The ability of health care professionals to communicate difficult messages effectively can be learned through directed education and practice.<sup>29–35</sup>

## 6. Family Support

PPC-PHC clinicians should aim to partner with and support parents throughout the course of the child's illness experience. In addition to addressing issues about the ongoing care of the child, PPC-PHC should aim to facilitate decision-making and help the parents and family cope with the ramifications of living with a serious medical condition. Practical support should include addressing family financial problems or facilitating access to mental health services. Spiritual support should be offered throughout the trajectory of care. Ideally, respite care should be provided. The family should be supported in carrying out important family, religious, or cultural rituals before and after a child dies. Counseling should be provided to the family regarding the potential benefits of additional genetic or metabolic testing of the patient for other family members or future reproductive decision-making. The possibility of organ donation should be addressed by qualified personnel. In addition to providing bereavement services before and after the patient's death, the PPC-PHC team is also encouraged to send a note of sympathy or attend the funeral.<sup>36</sup> Whether an autopsy is performed, provisions should be available to facilitate meetings of clinical staff and families who want to review the course of treatment or causes of the child's death.<sup>37,38</sup>



## 7. Sibling Support

Siblings of children with life-threatening conditions need attention and support. Health care team members should partner with parents to provide siblings who ask questions with age-appropriate and honest answers and to incorporate siblings in the routine activities of daily living and care of their ill brother or sister. Child life, art, music, and other therapists, as well as psychological and bereavement counselors based in the hospital or community, should be available to help siblings express and process their thoughts and emotions.

## 8. Health Care Staff Support

Support of all health care professionals, including the PPC-PHC team, is crucial to the well-being and continued ability of staff to meet the needs of families and children who have serious life-threatening or inevitably life-shortening conditions. The psychological, spiritual, and ethical needs of these health care professionals should be proactively addressed by PPC-PHC clinicians via peer-to-peer discussions, group debriefings, psychological and spiritual counseling, and educational programs.

## 9. Education and Training

All general and subspecialty pediatricians, family physicians, pain specialists, and pediatric surgeons should be able and willing to provide basic pain and symptom management to children and to request timely and appropriate pediatric palliative care consultations. PPC-PHC competencies should be a core part of medical school, residency, fellowship, and continuing education curricula as well as pediatric and subspecialty board certifying examinations. Specifically, these competencies should address interventions to manage pain and symptoms (including pharmacologic and nonpharmacologic methods),

specific aspects of end-of-life care, communication skills, decision-making support, ethical issues, and psychological and spiritual dimensions of life and illness, including personal feelings about anxiety and grief. Furthermore, dedicated efforts and initiatives to increase the workforce of PPC-PHC-trained subspecialty clinicians are vital.

## 10. Research and Quality Improvement

Rigorous observational and experimental research studies using quantitative, qualitative, and mixed methods are needed to improve the effectiveness of PPC-PHC interventions and policies. PPC-PHC teams should support and engage in research endeavors; all programs should have an active quality improvement agenda.

## 11. Ethical Considerations

The provision of high-quality PPC-PHC can raise a variety of important ethical considerations. The AAP has addressed the ethics of limiting or withdrawing life-sustaining medical treatment, including when anesthesia or a surgical procedure is needed to improve the quality of remaining life or to allow a patient to die at home.<sup>39–43</sup> The AAP has also addressed the special needs of children who have been abused.<sup>44</sup>

On occasion, the relief of severe intractable symptoms, such as pain or dyspnea, may include a rapid escalation in doses of analgesics and sedatives to the point of deep sedation, with the overriding goal of relieving the patient of pain or distress. Whereas palliative sedation for otherwise intractable suffering can be performed in an ethically appropriate manner, requests for euthanasia, assisted suicide, or hastening death cannot be granted but instead should be acknowledged and serve as a starting point of a conversation to elucidate the sources of suffering that often underlie such requests.<sup>45</sup>

PPC-PHC teams should ensure that their organizations have up-to-date institutional policies that address these issues and develop mutually informative relationships with hospital or organizational ethics committees.<sup>46</sup>

## 12. Financial and Regulatory Issues

PPC-PHC services must be paid equitably in hospital, ambulatory, and home settings by both private and public insurance. Payment systems based on relative value units and other current productivity measures do not compensate adequately for clinician time in providing decision support, complex symptom management, phone conversations, tele-health care, home visits, and care coordination, and therefore staffing of PPC-PHC teams should not be constrained by these metrics. In addition to patient-specific interventions, payment should also be provided for clinical decision-making support activities (eg, meetings with the patient or family, including perinatal meetings), respite for family caregivers, and bereavement interventions for the family even after the patient's death.

Current regulations should be modified by (1) broadening hospice eligibility criteria by expanding life expectancy criteria, (2) specifying that concurrent care includes all routine forms of life-prolonging care (eg, home nursing care) in addition to palliative care, (3) enabling provision of respite care and other therapies that benefit the child by benefiting other members of the child's family, and (4) ensuring that adequate payment accompanies these regulatory changes.

## CONCLUSIONS

High-quality PPC-PHC embodies core commitments that represent a fundamental promise to care for all children with serious life-threatening and inevitably life-shortening conditions and their families. Adherence to the guidelines

and recommendations affirmed in this policy will advance our ability to keep this promise and ensure that health care teams are appropriately resourced, trained, and positioned to provide excellent care.

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*Pediatrics* 2013;132;966

DOI: 10.1542/peds.2013-2731 originally published online October 28, 2013;

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