



Pediatric Palliative Care: Current Evidence and Evidence Gaps

Elissa G. Miller, MD^{1,2}, Carly Levy, MD^{1,2}, Jennifer S. Linebarger, MD³, Jeffrey C. Klick, MD⁴, and Brian S. Carter, MD³

Hospice and palliative medicine (HPM) is an emerging medical subspecialty initially recognized by the American Board of Medical Specialties in 2006. As the Institute of Medicine reported in 2014, health care delivery and the challenges of care at the end of children's lives have evolved significantly over the past 15 years.¹ The last decade has seen the growth of pediatric palliative care (PPC) programs at children's hospitals and a transformation of the field.² Fifty percent of children's hospitals nationwide have a PPC program, with a peak in new program development occurring in 2008.³ New programs are almost immediately impactful, experience high referral volumes, and must quickly expand their workforce.⁴ Although HPM has a growing body of literature, the evidence for PPC appears to lag behind the clinical growth.

Here we provide a focused and practical summary of evidence in pediatric HPM as a primer for those practicing in other subspecialties. Specifically, we review evidence by focusing on a few of the domains in HPM: (1) communication and psychosocial support; (2) pain and symptom management; (3) end-of-life care; and (4) ways to build a better health care system. We hope to strengthen understanding and partnerships between HPM and non-HPM clinicians and investigators and thereby improve patient care for children with serious illnesses.

Case 1

An 18-day-old, term infant presented to the emergency department unresponsive with sepsis and presumed meningitis. Blood and cerebrospinal fluid cultures confirmed group-B streptococcus infection. Given the serious nature of the infant's condition, the pediatric intensive care unit (PICU) team consulted the PPC team on hospital day 3. With aggressive life-sustaining measures, the infant survived, but sustained significant brain injury, remaining comatose with absent gag reflex and insufficient respiratory effort.

The PPC team met with family frequently during the infant's hospitalization to provide support around understanding of disease and coping with critical illness as well as to address goals of care. Initially, goals were focused on life-sustaining measures. As the severity of the infant's neurologic condition became clear, family goals slowly shifted toward a comfort-focused approach. Ultimately, after

a family meeting with extended family present, the parents chose to focus solely on the infant's comfort and discontinue all interventions that were prolonging suffering, including the ventilator. The infant died peacefully in his mother's arms shortly thereafter.

Case 2

A 15-year-old male with Hunter syndrome was well known to his hospital's PPC team. Many years earlier, his family, knowing the progressive nature of the disease, had chosen to focus on his comfort and quality of life. Enzyme infusions successfully reduced his pain and symptom burden, and he was rarely hospitalized during his first decade of life. Recently, however, he had experienced increased seizures with frequent aspiration events. After an episode of severe pneumonia requiring hospitalization and noninvasive ventilation, his parents asked to speak with the PPC team. Together, they devised an advance care plan for their son that included an out-of-hospital do not resuscitate (DNR) order. Utilizing the Concurrent Care for Children Requirement from the Affordable Care Act, the family chose to continue enzyme infusions while he also received home hospice care. Nine months later, the child had not been rehospitalized and was doing well, so the family discontinued hospice care but maintained the out-of-hospital DNR order. His parents continue to focus on his comfort and quality of life.

These cases present different but common scenarios facing PPC teams. A multidisciplinary approach to care allowed 2 different children—1 child with sudden, critical illness and another with chronic disease—to live what their families felt was the best quality of life for as long as possible under the circumstances of their illness. It is important to examine the evidence guiding the practices discussed in these cases.

Communication and Psychosocial Support

The literature within the communication domain of HPM focuses on family meetings, decision making, advance care planning (ACP), family coping, and the impact of bereavement. Although there is significant literature focused on adult patients, pediatrics necessitates a stronger focus on the child's cognitive development and how he or she fits into

ACP	Advance care planning
DNR	Do not resuscitate
HPM	Hospice and palliative medicine
PICU	Pediatric intensive care unit
PPC	Pediatric palliative care

From the ¹Department of Pediatrics, Nemours/Alfred I. duPont Hospital for Children, Wilmington, DE; ²Sidney Kimmel Medical College, Thomas Jefferson University, Philadelphia, PA; ³Children's Mercy Hospital and Clinics, Kansas City, MO; and ⁴Department of Pediatrics, Children's Healthcare of Atlanta, Emory University School of Medicine, Atlanta, GA

The authors declare no conflicts of interest.

0022-3476/\$ - see front matter. Copyright © 2015 Elsevier Inc. All rights reserved.
<http://dx.doi.org/10.1016/j.jpeds.2015.02.019>

the social structure of the family. These differences make it difficult to extrapolate from the adult-based literature.

Family Meetings

As in our case 1 example, family meetings are a cornerstone tool of HPM, but they have been minimally studied in pediatrics. Nonetheless, it seems clear that these meetings are infrequently used, even for the sickest children.⁵ In one study, meetings were focused on information exchange and future management. Conferences occurred predominantly for sicker patients, those with complex chronic conditions, and those with PPC consultation.⁵ Although many clinicians believe that the family meeting is key to the practice of palliative medicine,⁶ there is minimal evidence regarding families' perception of such meetings.

Decision Making

Clinicians can facilitate families' decision making. Hinds et al⁷ interviewed parents faced with making noncurative treatment decisions. The families identified components of being a "good parent" to include focusing on their child's quality of life, advocating for their child with the medical team, and putting their child's needs above their own.⁸ By working to define a family's priorities and values, the clinician can help them fulfill their wishes to "be a good parent" through dire circumstances.⁸ In a study of parents of PICU patients, 40% of parents preferred sharing decision making with their doctors, 41% preferred autonomous decision making, and 18.9% preferred delegating these decisions to their doctors.⁹

ACP

ACP involves the patient, family, and providers sharing information on the natural course of the child's disease, individualized prognostic information including trajectory, and the expected experiences of the child.^{10,11} ACP is a common task for palliative care teams; however, conversations are most productive when the family and clinicians have a common understanding of the child's disease and prognosis. On average, oncologists recognize 100 days sooner than parents that there is no realistic chance of cure.¹² When the poor prognosis for survival is disclosed early, there are earlier discussions of hospice care, earlier DNR orders, and decreased use of chemotherapy in the last month of life. Importantly, there are also better parental ratings of the quality of care in the home.

It is also important to include the child in ACP in appropriate ways. Teenagers with HIV/AIDS and those with advanced cancer overwhelmingly express the desire to participate in their own ACP.¹³⁻¹⁶ Families who decide to speak with their children about death report that they are happy with that decision, and nearly one-third of families who did not discuss death with their child regretted that decision later.¹⁶

A single-center study examined generally perceived barriers to ACP and DNR discussions. The top 3 barriers to ACP discussions identified were clinician perception of

unrealistic parental expectations, lack of parent readiness to have the discussion, and discrepancies between clinician and patient/parent understanding of the prognosis.¹⁷ The clinicians at that center overwhelmingly felt that ACP/DNR discussions should be initiated on presentation/diagnosis or during a period of stability.

Family Coping

Families cope and accommodate to their child's illness using a multitude of supports, coping strategies, and resources. Religion, spirituality, and life philosophy are some tools that can help families cope with adversity.¹⁸⁻²⁰ Hopeful thoughts and language play a major role; many parents use hopeful language about outcomes for their child, even when death is inevitable.¹⁸

Impact of Bereavement

The death of a child or sibling has a significant effect on the entire family. Youngblut et al²¹ reported significant negative physical and mental health outcomes in parents 13 months after their child's death, including newly diagnosed chronic health conditions, posttraumatic stress disorder, and hospitalizations. Psychiatric comorbidities, previous loss, economic hardship, duration and intensity of the child's treatment, perceptions of medical care, child's quality of life, and parent preparedness for death all impact parental outcomes.²² Siblings are affected as well and often recognize their parents' grief.²³ Survivor guilt, parental overprotection, and idealization of the deceased child affect sibling bereavement.²⁴ Siblings may be affected by how their parents engage them, allow them to see/hold/touch their ill siblings, and even participate in their care,^{25,26} although few evidence-based bereavement interventions have been published.²⁷⁻²⁹

Physical Aspects of Care

In contrast to the large body of evidence on palliative pain and symptom management in adults, studies on pediatric patients are scant. Much of the evidence that pediatric HPM clinicians use is drawn from the adult literature, and the medications used are often off-label. Although many of the principles of pain management are consistent across the age spectrum, there are important differences in neonatal and pediatric patients that merit more careful study. Even though the clinical practice of PPC includes symptom management integrated into life-sustaining therapies, much of the PPC literature focuses on pain and symptom management at the end of life.

Symptoms at End of Life

Children with terminal cancer have a significant burden of pain and symptoms in their last 30 days of life.³⁰ PPC has been shown to lessen this burden, and to help parents feel more prepared during their child's last months of life and at the time of death.³¹ Prominent symptoms in the last 24 hours of life include respiratory distress, pain, nausea, vomiting, and anxiety.³² One study found that children who die of advanced

Download English Version:

<https://daneshyari.com/en/article/6220856>

Download Persian Version:

<https://daneshyari.com/article/6220856>

[Daneshyari.com](https://daneshyari.com)