

# Virtual Mentor

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## MEDICAL EDUCATION 2

### Creating Training Opportunities in Pediatric Palliative Care

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Pediatric palliative care is inherently challenging. Practical and ethical considerations can be complex and compounded by the denial and grief that accompany the experience of losing a child. Palliative care for children with life-limiting illnesses includes provision of expert pain and symptom assessment and management, appraisal of spiritual and emotional needs, mindful communication between the professional care givers and the child and his or her loved ones regarding advance care planning, and bereavement care for the child’s family [1].

Pediatric palliative care shares many of the concerns of adult palliative care—the principle of proportionality, i.e., the calculation of burdens and benefits of various treatments [2]; the goals of care; and surrogate decision making. In addition to these, pediatric palliative care may involve the role of the child in decision making and the concept of the child as moral agent [3]. The questions of who shares in weighing diagnostic and prognostic information, determining the child’s best interest, and consideration of experimental therapies are complicated and are influenced by social and cultural norms. Legal questions—the status of the “mature minor” and the circumstances under which child protective services should be consulted—may also come into play [4].

Hence, students and residents preparing to care for pediatric palliative care patients must receive proper training in the pertinent ethical and legal issues. The values and goals of care for the child and family must be explored continually and re-established and redefined as the child’s disease progresses or its trajectory changes. Communication about end-of-life decisions is imperative, and much of what is considered “ethical” content is based in the substance and manner of this communication [3, 5]. In this paper we discuss challenges in and approaches to providing training in ethics and communication relevant to the care of pediatric patients who need palliative care.

### The Need for Training in Pediatric Palliative Care

In 2006 (the most recent data available), just over 53,000 children died between birth and age 19. (In the same year, 2,400,000 persons over the age of 19 died [6].) Among the most common causes of death in younger children (0-4) were developmental and genetic conditions present at birth, sudden infant death syndrome (SIDS), and cancer. Children over 5 were most likely to die from accidents (unintentional injuries) and cancer. After puberty, the chance of death by homicide or suicide increased [7].

According to the U.S. Department of Health and Human Services, 13 percent of children ages 0-17 (10.2 million children) have special needs [8]. While the majority of those children do not need palliative or hospice care, a sizeable portion do. To our knowledge, the number of children eligible for palliative or hospice care has not been quantified, but 24 percent of those counted as having special needs have conditions that significantly affect their activities, and, as a whole, such children have a death rate twice that of an age-matched unaffected population [9].

Children with multiple complex chronic conditions (CCC) have been shown to have a lower risk of rapid death than children with no or just one CCC, with longer hospitalization and periods of mechanical ventilation, and thus more opportunity for supportive care services [5, 10].

### **Pediatric Palliative Care Education**

The literature about pediatric palliative care suggests that neither pediatric residents nor their program directors feel that residents are adequately trained or prepared to care for children with life-limiting illnesses. In a survey of U.S. pediatric residency program directors and residents, 78.1 percent of program directors agreed that palliative care as a whole is important, and 99 percent of residents felt that it was important to provide pain and symptom management as well as psychosocial support [11]. Yet only 38.2 percent of program directors felt that their graduating residents were competent in pediatric palliative care, and 70 percent of residents felt that training in ethical issues in pediatric end of life care was inadequate or worse.

A second survey of 80 pediatrics residents at a major university medical center indicated low rates of exposure to dying children, and less than 50 percent of respondents reported that they had been taught how to hold discussions about withdrawal or limitation of life-sustaining therapy or autopsy, how to declare death or complete a death certificate, or how to provide follow-up support to families [12].

A third study asked 77 pediatrics residents in another major university medical center to rate their training, experience, knowledge, competence, and comfort in 10 different palliative care domains [12]. No mean response in any domain achieved even a moderate level of training, education, knowledge, comfort, or competence. All mean responses were within the range of “none” to “minimal,” and there were no statistically significant improvements associated with more years spent in residency [13].

A 2008 study of nearly 200 nurses’ and physicians’ perceived barriers to pediatric palliative care found that the factors most commonly perceived as interfering with optimal pediatric end-of-life care involved uncertainties in prognosis and discrepancies in treatment goals between staff members and family members; following these factors on the list were barriers to communication [14]. In addition, a qualitative study examining interviews of an interdisciplinary group of 17 pediatric

health care professionals identified lack of formal and informal preparation in pediatric palliative care as a major problem [15].

### **Training Opportunities**

Available data on the number of pediatric hospice and palliative care programs is not robust, but there are some indications that such programs are increasing in number. In a 2005 survey of 232 Children's Oncology Group member institutions, 58 percent of the responding institutions (including international) had a palliative care team, and 65 percent had hospice available [16].

Given those statistics, specific opportunities for pediatric residents to be involved in the care of children with life-limiting illnesses are not extensive, and those for medical students are even fewer. Despite this, physicians who will care for children at the end of life and for the families of those children must, at a minimum, learn pain and symptom management, spiritual and psychosocial assessment and care of patients and their families, interpersonal communication about goals of care, and decision making in the pediatric care context. When a medical student or resident is assigned to a patient with a life-limiting illness, thoughtful mentoring and debriefing directed toward the ethical issues that unfold in the course of caring for that patient can enhance the educational process. Designing methods that enable all students and residents to learn from every available teaching case in the environment helps maximize learning for trainees as well as for clinical teaching faculty. Because opportunities for personal experience with pediatric palliative care are limited, medical educators must not only make the most of those that *do* occur, but also provide alternative means for students and residents to consider the many aspects of care for dying children and practice the skills they need to provide expert care to the patients and their families.

### **Ethics Education in Pediatric Palliative Care**

The principal ethical paradigms for pediatric palliative care center on the patient's role in decision making. The concept that children have moral agency was first advanced by Franco Carnevale [3], who suggested that children are moral agents themselves and not simply derivatives of their parents and other adult family members. The implications of Carnevale's now widely accepted hypothesis can evoke great distress. Consider the case of a 14-year-old boy who developed a malignant tumor in his left arm. Although he knew that his best chance at a cure would be with amputation followed by chemotherapy and radiation, the boy could not bear the thought of an amputation and refused the surgery. His parents were devastated but supported his decision, which, understandably, raised concerns about the degree to which children should be allowed to make their own medical decisions. The 14-year-old's age-appropriate moral reasoning centered on the present and what he valued most—his body image, ability to play baseball and other sports, and looking like other children. This case has been used as a teaching case with first- and second-year medical students to prompt them to consider the idea of decision making by children and the maturity-related continuum of pediatric patients'

participation in decision making from “assent” (to treatment decisions made by others) to full consent or refusal of their own.

*Case studies.* Ideally, medical students’ experiences during rotation through their pediatrics clerkships would include care of a child with a life-limiting illness, but not all will have that opportunity. In the real world, their learning about pediatric palliative care may be limited to discussion of case studies facilitated by residents and faculty. Examples that present and resolve ethical dilemmas can be an effective way to practice ethical decision making while, at the same time, introducing specific clinical content areas in which direct patient care experience may be difficult to come by [17, 18]. The use of the 14-year-old’s refusal of amputation, for example, asks students to consider both the clinical facts of the case with its prognosis and treatment recommendations, and moral agency, parental autonomy, contextual elements of decision making, and the concept of the “mature minor.”

Case studies are an engaging way to teach and apply principles of medical ethics in a clinical context in the first and second years. In the third and fourth years, in most curricula, students encounter real patients and their families facing ethical dilemmas, and the issues become more compelling.

*Experiential learning.* Encountering patients and their families in difficult situations creates a rich “relational learning” opportunity that differs greatly from the information-based learning of the early medical school years and requires students to grapple with ambiguous questions for which there may be no “right” answer [19]. Supporting students in this new and complex process is a challenging responsibility for residents and clinical teachers. Using the students’ own experiences, in their own words, as the starting point for a discussion of ethical considerations can reveal much beyond the medical knowledge they possess [20, 21]. Information about the learning environment, cultural issues, and the student’s skills related to medical professionalism and empathy may emerge and become a more explicit part of the educational interaction. The experiential education that occurs when a student or resident takes part in the care of a patient, particularly when the patient is a child with a life-limiting illness, can be transforming. As the student or resident journeys with the patient and family, navigating treatment and other decisions, he or she gains new appreciation and understanding that is invaluable to the clinical and professional development of the trainee.

## **Conclusion**

Provision of palliative care to children with life-limiting illnesses requires the knowledge and skills for addressing the primary ethical principles of providing evidence-based, skilled medical care and shared decision making. Caregivers must also respect autonomy, deal honestly with the child and family, provide useful information, carefully and thoroughly weigh harms and benefits, and deliver care that is just, fair, and based on the needs of each child.

Ethics education in pediatric palliative care should center on the clinical aspects of care, whether it be through guided case studies or the experience of looking after a child in palliative care. Both approaches are valuable. Because there are, fortunately, a limited number of such cases, we must seize every opportunity for students and trainees to participate, when they can, in caring for these children and their families and, when they cannot, to learn from the experiences of those who have.

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