A Resident’s View of Pediatric Palliative Care

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When I tell people that I have chosen pediatric palliative medicine as my specialty, I usually hear one or a combination of the following: “Why would you want to do that?”, “What is that?”, or “It takes a special person.” Notably, I get the same comments from medical professionals and lay people alike. I believe these responses indicate the opportunities and challenges inherent in pediatric palliative care, both as a specialty field and within the realm of resident education.

‘WHAT IS THAT?’

My preferred definition of pediatric palliative care is, “Care aimed at easing the suffering associated with life-threatening conditions.” I believe that palliative care is an area that every pediatrician should study, along with infectious disease, neurology, and hematology. A solid foundation in the basics of each field allows us to provide quality care in common situations and to recognize the appropriate time to involve a subspecialist. Like any other subject, training in palliative medicine should begin in residency and continue throughout our careers.

Residency curriculum is designed to provide comprehensive training in pediatric care. We see patients in the clinic for both well-checks and sick visits. Caring for term newborns helps us to learn “normal,” while caring for premature neonates provides us with an opportunity to serve and learn from patients smaller and more fragile than we might have imagined. We care for children with emergency conditions (and sometimes not such urgent problems) in the emergency department, and learn the continuing care for them on the wards or in the intensive care unit (ICU).

The American Academy of Pediatrics statement regarding pediatric palliative care highlights the important role that palliative care should play in resident education. Despite this, research shows that pediatric residents largely feel unprepared when faced with the palliative care needs of their patients. The skills residents acquire through palliative medicine exposure include symptom management, complex care coordination, and addressing the core values of a patient and family. These principles are certainly applicable to the various situations that trainees and graduates eventually find themselves in. Despite the growing acceptance and implementation of pediatric palliative care, the integration of its tenets into practice and the appropriate use of its consultation services are still developing.

Although most general pediatricians are well equipped to address common presentations, children with potentially life-limiting conditions often have needs that would benefit from a palliative medicine consultation. Through proper residency training and continuing medical education, the partnership between palliative medicine and general pediatricians can and should flourish.

‘IT TAKES A SPECIAL PERSON’

I still don’t know how to respond to this statement. As pediatricians, we are all privileged to play an intimate role in the care of children and their families. As a result of our commitment, education, and position, parents often let us into their confidence in a ways that few others are allowed. This is true for any pediatrician.

While working with the palliative care team at Phoenix Children’s Hospital, I took part in care conferences including primary care physicians, pulmonologists, gastroenterologists, neurologists, and surgeons. Each participant in the care of children with life-threatening conditions brings a unique perspective that is indispensable in providing true palliative care. Residents need to seek out these opportunities to see physicians and families coming together as a team to serve patients.
Pediatricians take care of children — some of whom might have life-threatening conditions — in the clinic, the ICU, the emergency department, and the wards. Each interaction is meaningful and important in its own way, and may even be the beginning of an episode which ends with a child’s death. Our interactions with children and their families take on a special importance in the middle of the night, when parents are physically and emotionally exhausted. It is in these moments that, even as trainees, we may have a great impact on the care offered to a child who is suffering. Our actions and words, along with our inactions, will have a lifelong impact on the child’s family as well.

Recently, one of the interns in my program had just such an opportunity. On the day prior to taking call she attended a noon conference on advance care planning. She made a goal to do more to facilitate such discussions. That night, a child who had been very ill for some time was admitted to her care. Newly sensitized to the potential for the child and family to suffer and newly armed with increased skill, knowledge, and confidence, she gently addressed limitations of resuscitative attempts (“Do Not Resuscitate” orders) with the family. Little did she know she was providing continuity in a discussion that had evolved over several months and that included the child’s primary care physician, palliative care team, the extended family, and trusted clergy. The family was ready at that moment to make a decision. This intern, by virtue of her invitation to discuss the issue, enabled their concerns to be addressed and their wishes to be honored as she translated them into written orders and concrete actions. This is just one example of how a well-trained general pediatrician can provide elevated care using principles of palliative medicine.

Pediatric palliative medicine is moving forward to the great benefit of patients and their families. Residents and practicing physicians stand to grow as they learn what it means to provide palliative care and incorporate it into their clinical paradigms. Pediatricians have an opportunity to care for children during the full spectrum of health, including illness and even death. Palliative medicine skills and knowledge are necessary tools for all of the “special people” who provide health care for children.

REFERENCES