

Pediatric Palliative Care: Making Every Day the Best It Can Be



A small stack of books sits on Kathy Perko's desk at OHSU Doernbecher Children's Hospital in Portland, Oregon. The titles range from "We Were Gonna Have a Baby, But We Had an Angel Instead" to "Lifetimes: The Beautiful Way to Explain Death to Children." Perko, M.S., C.P.N.P., is the program director of Bridges Palliative Care at OHSU Doernbecher, and the books she shares with families are just one of the many ways she and her team help them cope with caring for, and sometimes saying goodbye to, their critically ill or injured children.

Perko started her career at OHSU Doernbecher as a nurse in the pediatric oncology department. She had been there for a few months when a small group of parents came to see the pediatric oncology team, including Kathy, after their children had died at home following hospitalization. They told the team that after their children left the hospital, they had become completely disconnected from the nurses who had been a big part of their lives during the course of their children's illnesses. According to Perko, "They told us we could do better." Motivated by a desire to do better and consistently deliver patient-centered and family-oriented care, Perko—along with a group of nurses, a social worker and a child life therapist—founded the Bridges program in 2005.

While some consider Perko's work as a pediatric palliative care nurse practitioner impossibly difficult, it is a calling that fulfills her because of the relationships she builds with each child and family. Relationships are the very essence of palliative care, especially in pediatrics where a young patient's connection to family, physicians, nurses, social workers, chaplains and others can make all the difference in their quality of life during a serious illness or following an injury.

Thanks to advances in medicine and technology, seriously ill and injured children are living longer and the need for pediatric palliative care is growing faster than the number of programs or practitioners can provide. There are several reasons for this lag, including a lack of

understanding that critically ill or injured children have different needs than adults. There is also a tendency to deny the reality that some childhood diseases are not yet curable.

Children's hospitals are places where parents go for miracle cures. "If the mantra is that we're stamping out disease, that makes it hard for pediatrics to find its place," says Dr. Renee Boss, associate professor of pediatrics at the Johns Hopkins University School of Medicine and founding member of The Palliative Care Working Group in the Neonatal-Perinatal Medicine division. "You have to acknowledge there are diseases we're not stamping out in order to acknowledge the role for pediatric palliative care."

Making pediatric palliative care more accessible requires all stakeholders to recognize the unique needs children have while balancing competing priorities. Insurance companies, hospitals and public funders are called upon to carry forward the important work that many palliative care clinicians and private philanthropy organizations have forged over the last two decades.

A Different Kind of Care

Pediatric palliative care is a complex specialty that spans multiple phases of childhood development, from perinatal through young adulthood, and may be provided at any stage of illness. It is often confused with hospice, which is reserved for patients who are

expected to live six months or less and are no longer receiving curative treatment. Pediatric palliative care is also not necessarily well distinguished from adult palliative care despite the fact that there are important differences.

Similar to adult palliative care, the pediatric specialty provides an extra layer of support for patients living with serious and life-limiting illness or injury, as well as for their families. It aims to enhance the quality of a child's life by reducing pain and suffering while also helping to ensure that informed treatment choices are consistent with their values and preferences. An interdisciplinary care team consisting of specialty-trained doctors, nurses, social workers, chaplains and other specialists work together to execute a child-centered and family-oriented care plan.

Children's needs are very different from those of adults, however—especially in the following areas:

- **Decision-making:** Most children must rely on their parents or guardians to make decisions for them. Often the parents are young and may not have experienced illness or death in their families, causing them to second-guess their decisions and bear a sense of intense guilt about making the “right” decisions for their children.
- **Advance care planning:** While many adults may have outlined their wishes for care through advance care planning, children have rarely documented their preferences.
- **Life-prolonging therapies:** While the death of someone's 95-year-old grandmother is a sad occurrence, it may not necessarily come as a surprise. It is more difficult to accept that a child with a critical illness or injury may die. As a result, some children receive complicated medication regimens and advanced technology to prolong their lives, often contrary to their best interests and despite their wishes.
- **Range of diseases:** Children experience a wide range of diseases that rarely occur in adults, thereby making care more complex and often using treatments that have been proven effective only for adults.
- **Developmental challenges:** Children may be living with serious illness for months or years, growing and developing throughout the trajectory of their diseases. Not only are their bodies changing, their cognition is too—affecting how they view their illness and the idea of death overall.

Through its interdisciplinary approach, the palliative care team addresses these complexities from the time of diagnosis throughout

the course of disease, always focused on family relationships and making daily life better for the child. This approach is centered on helping patients live as well as they can for as long as they can. Perko explains, “It might mean getting a child an extra set of school books so they don't have to carry them to and from school. Or finding community resources for a patient's siblings to help them cope with their brother's or sister's illness.” She stresses that pediatric palliative care isn't a one-time consult. It's about an ongoing relationship and about “hope and hoping for something different.”

One of the chief differences between pediatric hospice and palliative care may come down to reimbursement. The Medicaid hospice benefit covers children. Yet, state Medicaid programs generally follow Medicare hospice guidelines for adults. In the past, parents were often forced to make the agonizing choice of whether to enroll their children in hospice, discontinuing curative treatment, or continue treatments that could potentially prolong their lives. The Affordable Care Act (ACA) remedied this painful dilemma. Now children who have Medicaid can receive both palliative and hospice care in their last six months of life.

For a family working to make ends meet, the reimbursement distinction is meaningful. Parents seek assurances that their child will receive the services they need to be comfortable and happy at all stages of their illness. Payment models should support concurrent palliative and curative care for children, starting at the time of diagnosis. Helping people understand that pediatric palliative care does not necessarily mean hospice, and thereby end of life, is one of the keys to spreading its adoption and enhancing the quality of life for seriously ill children.

The Need for Specialized Pediatric Palliative Care

While society may be hesitant to accept the fact that children experience illness, injury and even death, statistics clearly demonstrate the need for pediatric palliative care.

In 2014, there were 41,881 deaths in children between 0 and 19 years of age, accounting for 1.59 percent of all total deaths in the United States.ⁱ Furthermore, over 500,000 children in this country are living with complex chronic conditions—a population that consumes up to one-third of the health care spending on children.ⁱⁱ

Just over twenty years ago, services to ease the suffering and pain for critically ill and dying children did not exist. The research to highlight the need for these services was also absent. Dr. Joanne Wolfe changed that.

During her pediatric hematology oncology fellowship training, Wolfe had several experiences that revealed the need for a more comprehensive, standardized system to care for children suffering from serious illness.

“I was at the bedside with children who were in extreme pain and we were recreating the wheel each time we cared for them,” she says. “There weren’t any standards of care, so there was great variability in communication and decision-making.”

With the support of a three-year grant from the Hasbro Children’s Fund, Wolfe established the Pediatric Advanced Care Team (PACT) at the Dana-Farber Cancer Institute in 1997, the first pediatric palliative care program in the United States. Three years later, she and her colleagues published their first studies in the *New England Journal of Medicine* and the *Journal of the American Medical Association*, which revealed that an overwhelming majority of bereaved parents felt their children had suffered a great deal in the last months of their lives.

There was also evidence that clinicians wanted more guidance. In 2009, Bridges received an expansion grant from the Cambia Health Foundation. Kathy Perko and her team used the grant to survey community hospice nurses in Oregon and Southwest Washington to assess their educational needs in the area of pediatric palliative care. The findings revealed that hospice workers needed assistance with pediatric pain and symptom management, communication with children and parents, a better understanding of pediatric illness and death, and help with ethical issues. In response, Perko and her team developed a pediatric palliative care curriculum, with regional education in four cities and web-based training that covered topics the hospices selected.

Growth in Pediatric Palliative Care Programs

Before Kathy Perko established Bridges, 80 percent of the children they cared for with cancer died in the hospital. Today, 80 percent die at home. “That’s a win, because that’s most often what the family wants,” she says. But, it’s not easy to accommodate a child’s needs in small, rural or remote communities.

In 2011, the Cambia Health Foundation funded a telehealth grant for Perko and her colleagues to consult with adult hospices in rural communities, enabling children in those communities to stay in their homes with support from hospice professionals and Bridges staff. “We have to think outside the box to make it all work,” Perko explains. “But when families get to do what’s important to them, there’s no amount of time we wouldn’t spend to have that happen.”

Other programs across the country are having positive impacts too. Dr. Wolfe cites a 2013 study that showed a 69 percent penetration rate for pediatric palliative care programs in a survey of 162 hospitals as proof that the specialty is on a positive trajectory.ⁱⁱⁱ “The services are being introduced earlier on, often at the time of diagnosis, so we can follow these children longer, which is a great improvement,” she says.

Debbie Lafond, one of the founding members of the Pediatric Advanced Needs Assessment (PANDA) Care Team at Children’s National Health System, says when the PANDA program was fully funded in 2012, they saw 50 patients. Today, they’re seeing over 200 new patients a year, which doesn’t include the patients they see repeatedly.

Like Bridges, PANDA cares for patients and consults with local hospices. In 2015, the Cambia Health Foundation awarded Lafond a two-year, \$180,000 grant through the Sojourns Scholar Leadership Program. With the grant, she and her team have been able to provide year-long intensive training programs for palliative care team members—staff nurses, child life specialists and chaplains—as well as community hospice partners to help them feel more confident in caring for their pediatric palliative care patients.

“By 2000, our hospice program had closed,” explains Lafond. “It was cost prohibitive to see patients outside the hospital. Now we partner with hospices in the community and use them as palliative care clinicians. We have educated and mentored them in upstream care, how to address symptom control and quality of life more broadly. We want families to have relationships with these folks.”

Lafond also ensures PANDA staff are cared for. “We have to take care of our staff so they can take care of our patients,” she says. “Caring for sick children is hard work, because you’re not just caring for the child, you’re caring for the parents, siblings, grandparents, friends, peers from church and others involved in that child’s life.”

If a child dies, PANDA has a medical debriefing and often a psychosocial debriefing for staff to talk about how they’re feeling. They have a yearly bereavement service for staff to support each other in grieving for and remembering the patients they lost. They also hold monthly debriefings on various units to encourage everyone to discuss their feelings and how they’re coping.

Areas of Opportunity

For Lafond and the PANDA team, a simple question guides them: “What can we do to make every day the best it can be for these patients and their families?” It’s a guiding principle that should be a standard of care for all critically ill or injured children. To achieve this standard, the following areas need more attention:

- **More understanding of the field:** People need to know that palliative care isn’t scary—that it doesn’t signal end of life. The approach is about living well each and every day. While advances in medical technologies are helping seriously ill children live longer, palliative care is vital to ensuring they experience quality days.

- **Funding:** Private philanthropy has funded many of the pediatric palliative care programs thus far. Hospitals, public funders and private payers need to step up to support programs and benefits that extend beyond medical needs to also include other services, including occupational, physical and speech therapy. Stakeholders must recognize that children are different from adults and require different care and coverage. Critically ill children have pre-existing conditions and need benefits to protect them for what could be decades. Dr. Boss says, “It’s easier now for payers and hospitals to wrap their heads around paying for six months of hospice rather than twenty years of palliative care.” Concurrent palliative and curative care should be the norm for children with serious illness or injury.

At the same time, family members need support to ensure they don’t lose their jobs when caring for a child, which could also mean losing insurance coverage. There should be better benefits to cover in-home caregiving, whether a parent or caregiver service provides it.

- **Home care:** Being able to provide palliative care for children at home should be a standard of care. According to Perko, caring for children at home requires a “three-legged stool.”
 1. The family who knows their child better than anyone.
 2. Community-based palliative care and hospice programs that care for children in their homes. Currently, many of these programs are focused on adults and require extra support from hospital-based palliative care teams.
 3. Hospital-based palliative care teams with the expertise to guide palliative care and hospice services in the community.

If one of these legs fails, Perko says they won’t be as successful in meeting the needs of children and families.

- **Workforce investment:** Philanthropic initiatives such as the Cambia Health Foundation’s Sojourns Scholar Leadership Program have made investments in the development of a pediatric palliative care workforce. While there are more pediatric palliative care programs than there were ten years ago, there remains a shortage of skilled clinicians to handle all the work. Dr. Boss, a Sojourns Scholar, says hospitals need to make an investment to change this, hiring the staff to meet the unmet needs. “Over half of the current programs are funded by philanthropy,” says Boss. “We need to pressure hospitals, so clinicians don’t have to go out and raise their own salaries.”
- **Training:** Given the number of children living with chronic and life-threatening medical conditions, and the complexities of

caring for them, the practice of pediatric palliative care is sorely understaffed. The field needs more fellowships to train physicians and more faculty to teach clinicians. Studies show that few directors of pediatric residency programs feel that graduating residents are competent in the field.^{iv} Furthermore, palliative care should be taught at the basic undergraduate level, so graduating physicians know how to have conversations with families and understand when to refer them for palliative care.

- **Evidence-based research:** For the most part, research in this field has been based on data from treating adults. Clinical trials are difficult because of the relatively small number of critically ill children, the incredible diversity of diseases they experience and the lack of trained investigative researchers. However, with funding from the National Institutes of Health (NIH), Dr. Wolfe and her colleague, Dr. Chris Feudtner, founded the Pediatric Palliative Care Research Network (PPCRN) to improve the quality of care for children with life-threatening conditions and their families. Parallel efforts should expand on this work to ensure that decision-making is based on more than anecdotal evidence.

A Call to Action

Pediatric palliative care is an important area of medicine—one with meaningful differences from adult palliative care. Pediatric palliative care is less well funded. And when a child has a serious illness or dies, the loss affects everyone in the family. These differences make it an area both philanthropists and policy makers should consider addressing. Today, programs such as Bridges, PANDA and PACT are shining examples of programs that are working, building meaningful relationships with children and their families to help them live each day with quality, according to what that means for them.

Despite significant progress, there is more to be done. Cambia Health Foundation is helping accelerate change by establishing the Cambia Health Foundation Endowed Chair of Pediatric Palliative Care at OHSU Doernbecher Children’s Hospital—one of only three such chairs in the United States. In this role, Robert Macauley, M.D., FAAP, FAAHPM, is building on Kathy Perko’s phenomenal contributions to the Bridges program while collaborating with her and other national leaders to seize opportunities that will advance the field of pediatric palliative care.

As Nelson Mandela said, “There can be no keener revelation of a society’s soul than the way in which it treats its children.” We have a moral obligation to do better for our children, ensuring pediatric palliative care is readily accessible to patients and their families who need an extra layer of support.

¹Deaths: Final Data for 2014; National Vital Statistics Report. Centers for Disease Control and Prevention 2016.

²Huang I.C., et al. Measurement for Children with Life-Threatening Conditions: Limitations and a New Framework. *Child Indic Res* 2011 4(1): 145-160.

³Feudtner C, et al. Deaths. Pediatric Palliative Care Programs in Children's Hospitals: A Cross-Sectional National Survey. *American Academy of Pediatrics* 2013.

⁴Baker JN, et al. National survey of pediatric residency program directors and residents regarding education in palliative medicine and end-of-life care. *Journal of Palliative Medicine* 2007: Apr; 10(2): 420-9.