Pediatric Palliative Care Gains Recognition

By Kristine Crane

P alliative care is not commonly associated with pediatrics, but pediatric palliative care programs are growing throughout the country—not as children die, but as they live longer with serious illnesses. A study published in the May 10 issue of Pediatrics showed that 70% of children were alive one year after their first consultation in a palliative care program.

The study, called “Pediatric Palliative Care Patients: A Prospective Multicenter Cohort Study,” surveyed 515 children in palliative care programs at six children’s hospitals in the U.S. and Canada. According to Chris Feudtner, M.D., the director of research at the Pediatric Advanced Care Team at the Children’s Hospital of Philadelphia, and one of the study authors, unlike adults in palliative care programs, who have an average lifespan of two weeks, children often need ongoing care. “There are plenty of people who are re-admitted, which means we have to have a staff ready to handle new incident and prevalent cases,” he said.

But many palliative care programs are understaffed, with just one physician who may be part-time, along with a nurse, and may a social worker and a chaplain who are usually volunteers, Feudtner explained. “A lot of places say they have a palliative care program, but they really have a silhouette. The gold standard is an inter-disciplinary team—one that is staffed with a few physicians, a full-time nurse, a psychologist, chaplain, and social worker who are not doing it pro-bono.”

That team approach from the onset of a child’s illness avoids the potential for using palliative care merely as a last resort, said Sarah Friebert, M.D., the founding director of the Haslinger Family Pediatric Palliative Care Division at Akron Children’s Hospital in Ohio. “The team approach allows you to see the whole spectrum; then you’re not bringing in the family at the worst possible time.”

Friebert said improvements in medications, technology and treatments, along with earlier diagnoses, account for children’s increased longevity with all types of conditions. A century ago, 30% of deaths in the U.S. were in children under age 5, today deaths in children from infancy through age 19 account for just 2.2% of all deaths. According to the Pediatrics study, the leading conditions among children in palliative care programs are genetic and congenital, affecting 40.8% of the children surveyed, followed by 39.2% with neuromuscular disorders, and 19.8% with cancer. The study also showed that 17% of children were younger than age 1, 37.5% were between 1 and 9, 30% between 10 and 18, and 15.5% aged 19 or older.

Feudtner, a pediatrician by training, said that it’s important for physicians on pediatric palliative care teams to be able to handle many types of patients. “I think that you deepen your sense of what is most salient as a palliative care physician if you actually take care of kids outside of one sub-specialty,” he said, adding that most issues addressed in the programs are universal, such as bereavement and psychosocial support for family members.

Pediatric vs Adult Care

In fact, the importance of a hands-on, holistic approach distinguishes pediatric palliative care from adult palliative care, especially for cancer patients. According to Joann Wolfe, M.D., the director of Pediatric Palliative Care at Children’s Hospital in Boston, “The biggest challenge to caring for children with cancer at advanced stages is the emotional considerations of everyone who is involved,” Wolfe said. “It’s just very natural among most parents to not to want to leave any stone un-turned in terms of cure of child or keep alive as long as possible.”

Rather than urging parents to let go, Wolfe added, physicians need to integrate palliative care into children’s care, which may include Hospice services. The Patient Protection and Affordable Care Act passed in 2010 made it possible for children with life-limiting conditions to receive medical treatments concurrently with Hospice. Previously, patients had to relinquish disease-directed therapy to enroll in Hospice. However, the new legislation still mandates children in Hospice must have a prognosis of six months or less.

Some states, such as Massachusetts, have devised their own law to overcome that barrier. Massachusetts created a state-funded pediatric palliative care network that allows children to concurrently enroll in Hospice and receive medical treatments, without a life expectancy requirement. A study on the program published in the June 20 issue of the Journal of Palliative Medicine showed that fewer than 5% of the children enrolled in the program in 2010 died, and a majority of parents felt their child received excellent care.

Wolfe said the law is a step in the right direction, since a six-month prognosis excludes families who for emotional reasons wouldn’t enroll their children in Hospice because they wouldn’t want to equate their child’s condition with death. Oftentimes, a child’s prognosis is more uncertain than an adult’s, and children can be surprisingly strong, Wolfe added. She recently had one such patient with advanced neuroblastoma. “Three to four weeks ago he really appeared to have reached the end of his life, but with some medication he turned around dramatically,” she said. “He was able to go on vacation with his family, even though the trajectory was still that his life will end. It was one of those reminders that even though you think child reaches death imminently, they are incredibly resilient.”

Still, Wolfe cautions against thinking palliative care necessarily extends life. “I wouldn’t want to promote that as a promise. I think it’s really reassuring that we aren’t shortening life,” she said, adding that the New England Journal of Medicine study published in August 2010 showing palliative care improved survival outcomes in non-small-cell lung cancer patients could be “highly replicable” for pediatric cancers.

And when children do die—as roughly 50,000 do each year in the U.S.—they often resemble adults, according to Feudtner.
“[There is] the same wonderful focus on what matters most and embrace of family and how to love each other and do right by each other that I’ve heard about people at the other end of the age spectrum,” he said.

Assessing Children’s Needs

Since parents are charged with making most medical decisions for children under the age of 18, researchers are also trying to give minors more voice in their own care. An initiative called PediQUEST surveys children and their families about symptoms and care. Abstracts of studies published in January edition of the Journal of Pain Management showed pain, nausea and fatigue are the top three stressors among children. Researchers are hoping the initiative will help them understand how to better coordinate children’s medications, since they may be taking as many as 18 at a time, according to Friebert. “We start therapies in medicine and we don’t necessarily evaluate if kids should still be on those,” Friebert said, adding there is a greater tendency for the “compounding effect,” or multiple drug interactions. That’s happened because many drugs are only tested in adults.

To help overcome this, in 2007, Congress re-authorized two laws, the Best Pharmaceuticals for Children Act (BPCA) and the Pediatric Research Equity Act (PREA), which encourage drugs companies to study their products in children. Between 2007 and 2010, 130 drugs have been studied in children. Congress also re-authored $200 million for a pediatric research fund at the National Institutes of Health.

Palliative medicine has been included as a criterion for ranking children’s hospitals by US News and World Report since 2006, the same year experts started pushing for multi-center studies like the one in Pediatrics. “The picture has changed what end-of-life care looks like,” said Friebert. “When we say that palliative care is not about death and dying, we really mean it.”

Another initiative Friebert hopes will highlight the needs of children in pediatric palliative care programs is the recent joint commission certification for which all hospitals, including children’s, can apply. “It means palliative care has risen to a level of importance in hospital-based practice,” she said. “We’ve been advocating for this for years. It’s a measure that has finally arrived.”

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