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The Challenges of Palliative Care for Children

So much about treating seriously ill children is different from caring for adults

Pediatric palliative care is 'a journey of ups and downs' in trying circumstances, says Chris Feudtner, center, with Tammy Kang, left, and Gina Santucci, all from the care team at Philadelphia Children's Hospital. *PHOTO: WILL FIGG FOR THE WALL STREET JOURNAL*

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Palliative care is increasingly used to help seriously ill adults and seniors. Now medical centers are creating teams that specialize in a more challenging task: delivering palliative care for young children.

Despite a popular misconception, palliative care isn't just about keeping patients comfortable until they die. Rather, palliative-care teams complement the usual array of physicians, specialists and clinicians, helping patients by managing pain, treating

symptoms and ensuring that they have the best possible quality of life.

Pediatric palliative care is modeled on the principles of adult palliative care. But because so much about treating seriously ill children is different from caring for adults, it presents its own unique set of challenges.

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"It's outside the natural order of things for children to be ill," says Joanne Wolfe, director of the Pediatric Advanced Care Team, or PACT, at Dana Farber/Boston Children's Hospital. "That creates a greater emotional toll on families. Palliative care adds an extra layer of support."

Extended Lives

In contrast with adult palliative-care patients, the majority of whom have cancer, about half of children in palliative care have complex genetic and neurological diseases that in previous generations would have been fatal. Because medical advances have extended these children's lives, pediatric palliative care is often delivered for far longer, and with a wider range of specialists, than adult palliative care.

About half of children's hospitals in the U.S. have pediatric palliative-care programs, according to a 2013 survey in the journal Pediatrics. There are no official standards, and programs range from well established to consisting of two or three volunteers.

The PACT at Dana Farber/Boston Children's, created in 1997, comprises about 10 people, including attending physicians, a pediatric nurse practitioner, a clinical and pediatric-palliative-care social worker, and an interfaith clergy person. Members work in tandem with a child's primary physicians, evaluating the child's comfort and family needs, and meet regularly with the families to discuss their values and to prepare parents for the decisions they will face.

It's difficult to measure how many children receive palliative care nationally. However, between one million and two million children in the U.S. have the kinds of complex conditions that could benefit from palliative care, says Sarah Friebert, director of pediatric palliative care at Akron Children's Hospital in Ohio. Referrals to the PACT at Dana Farber/Boston Children's have grown at least 10% a year since the hospital started tracking the data in 2001. A hospital spokesperson says the team now treats about 500 children a year.

One of the challenges is helping families deal with the often bewildering range of medical specialists assigned to the complicated cases of seriously ill children. Communication and decision making can take longer, and sometimes the delivery of care can stall. Pediatric palliative-care teams can help families work through competing advice and clarify treatment decisions.

Two years ago, a New Jersey infant, Isaiah Jones, was gravely ill with a rare genetic disorder called idiopathic arterial calcification, which causes a buildup of calcium in the arteries. Isaiah suffered from worsening heart failure and severe brain damage and was attended by neurologists, cardiologists, nephrologists, pulmonologists, gastroenterologists and other specialists. The PACT at Children's Hospital of Philadelphia provided palliative care.

Isaiah began having repeated coughing episodes, causing him to choke and have seizures. He was hospitalized several times for respiratory failure. Believing that enlarged tonsils might be obstructing his throat, the PACT recommended a tonsillectomy. But ear, nose and throat specialists feared the procedure would cause Isaiah to choke and his condition to worsen.

The PACT met to discuss the situation and to assess all of the reasons for and against the proposed surgery. Then it laid out the case for and against to Isaiah's mother, Monica

Jones. She approved the surgery, the infant's tonsils were removed, and his seizures have ceased.

Most sick adults can make their own decisions. Not so with children, whose parents must make calls about what treatments to try and when treatments should stop. Palliative-care providers help guide parents through the wrenching choices.

Richard Goldstein, a doctor on the PACT at Dana Farber/Boston Children's, tells of treating a young patient, Cameron Lord, who was born with Tay-Sachs, a rare, incurable hereditary disease that destroys nerve cells in the brain and central nervous system. Dr. Goldstein advised the girl's parents, Blyth and Charlie Lord, how the disease would progress, including grand mal seizures and bouts of pneumonia. He also prepared them for decisions they would face about feeding tubes, and, ultimately, when to continue or stop their daughter's treatment.

By Cameron's third bout of pneumonia, Dr. Goldstein offered to treat her at home with antibiotics. But the Lords asked him to move solely to comfort care. Cameron died five days later.

"The palliative care Cameron received from Dr. Goldstein helped her have the best life she could have had," says Ms. Lord, "and that has made all the difference in how we remember."

Trial and Error

One of the biggest challenges in treating critically ill children is that they are often too young or too impaired to effectively describe their pain. Compounding the difficulty, prescribing drugs to relieve their pain can be hampered by a lack of research on medicating children. Palliative care in such cases often requires trial and error.

In 2013, the PACT at Children's Hospital of Philadelphia was caring for an 18-month-old with mitochondrial disorder. The child, suffering progressive brain injury, cried continually for weeks and experienced spells of vomiting that lasted for hours. No tests identified the cause of the symptoms. The PACT's doctors tried one drug combination after another to ease the child's suffering, including medications to ease stomach-acid irritation, drugs to calm the child and opioids to ease the pains.

The team discussed the child's case at weekly meetings, with each doctor offering ideas

for what to try next. At one point, the team leader, Chris Feudtner, noticed the angle of the baby's head was lopsided. He suspected abnormal muscle tone might be the cause, so the PACT added drugs to address that. Eventually, the baby's discomfort stopped.

In delivering pediatric palliative care, Dr. Feudtner says, "we embark on a journey of ups and downs in what are the most emotionally challenging circumstances that anyone ever encounters."

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