

# Improving Access to Pediatric Palliative Care

*Neuromuscular and neurodegenerative disorders are among the leading life-limiting diseases.*

BY CHRISTINE KILGORE

Dr. Stefan J. Friedrichsdorf has a list of “myths” about pediatric palliative care that he presents during lectures. Among them: that the death of a child in the United States is a rare event, that pediatric palliative care is just for children with cancer, and that care starts when treatment stops.

In his lectures – and in his work every day at Children’s Hospitals and Clinics of Minnesota, Minneapolis – Dr. Friedrichsdorf debunks these myths.

In January, he was one of two pediatricians who won national awards from the Hastings Center and a partnering foundation for their contributions to the field of palliative care. He and pediatrician Savithri Nageswaran of Brenner Children’s Hospital at Wake Forest University Baptist Medical Center in Winston-Salem, N.C., joined two geriatricians and an internist in receiving the award.

The pain and palliative care program at Dr. Friedrichsdorf’s institution is a relatively long-standing program, but pediatric palliative care is a new subspecialty and is still a relatively new area of pediatric care and of palliative medicine – one for which delivery models and educational pathways are still evolving, and one for which reimbursement is poor and regulatory barriers are challenging.

“It’s truly interdisciplinary, in that people need to really go beyond what they’ve been trained for,” said Dr. Friedrichsdorf, medical director of the department of pain medicine, palliative care & integrative medicine at Children’s. “I’m nothing without my team.”

Pediatric palliative care has been defined and described by the World Health Organization, the Institute of Medicine, the American Academy of Pediatrics, and other bodies as individualized, integrative care that is provided for children with life-threatening conditions. The care starts at diagnosis, continues through the trajectory of the illness, and is directed at the underlying illness and at the physical, emotional, social, and spiritual needs of the child and family.

More than 15,000 children and teens die in the United States each year from life-limiting diseases – and less than a quarter of them have cancer, according to data cited by Dr. Friedrichsdorf. Neuromuscular or neurodegenerative disorders cause a significant proportion of those deaths, followed by congenital or genetic disorders, cardiovascular disorders, and metabolic disorders.

“The vast majority of these children do not have access to pediatric palliative care in this country,” Dr. Friedrichsdorf said in an interview. Data show that these children are suffering needlessly from pain, breathlessness, nausea, and vomiting.

Praised by the awards committee for “innovative symptom management,

compassion, and family-centered care,” Dr. Friedrichsdorf said he and his team take “an extremely aggressive approach” to managing pain and distressing symptoms in children with either life-threatening or life-limiting conditions.

He believes strong pain medications are underused in children (and one of the “myths” he debunks is that increasing doses of opioids and/or benzodiazepines causes respiratory depression and quickens death), but also that pharmacology alone is insufficient.

His department employs both pharmacology and complementary therapies such as biofeedback, massage, hypnosis, acupuncture, and acupressure. Physicians and other staff are trained in such modalities. “It’s not one or the other. It’s using the whole breadth [of therapies] at the same moment,” said Dr. Friedrichsdorf, who is trained in self-hypnosis.

“We want to promise each family, if your child is suffering from distressing symptoms like nausea, pain, or dyspnea, we can usually make these symptoms go away,” he said. “Our goal is for children to live as long as possible, as well as possible.”

In addition to physicians and nurses, the pain and palliative care team at Children’s includes social workers, psychologists, a physical therapist, a child-life specialist, massage therapists, and advanced practice nurses.

Each of these professionals can see patients as part of a hospital-based pain and palliative care “rounding team” in the department’s pain and palliative care clinic, or for patients in the Minneapolis/St. Paul area, in the home through the department’s home-based component. The team can be called upon by anyone – a doctor, a patient, a relative, or a friend – for a consultation, and its members meet regularly to discuss patients.

“My physical therapist may tell me, for instance, that I need to change [a patient’s] pain medications because she sees side effects,” Dr. Friedrichsdorf said.

A pilot study of pediatric palliative care teams at eight children’s hospitals, to be published soon, found that professionals in the teams had a “clear idea of what the other professionals offered to the patient and family,” said Nancy Berlinger, Ph.D., deputy director and research scholar at the Hastings Center, which conducted the study with researchers at Rush University, Chicago.

A chaplain knows, for instance, how the physician and nurse are addressing the patient’s medical needs, and the physician is aware that the chaplain is supporting the parents and, in some cases, the child, she said in an interview.

“Having shared goals of care and strong communication is also important so that everything doesn’t have to be explained every time a shift changes or a patient is transferred to a different setting,” she said.

“Most of these pediatric palliative care teams are fairly newly established,” Dr. Berlinger noted.

Dr. Nageswaran, who led the establishment of the first pediatric palliative care program at her hospital in 2008, said she was struck by the amount of coordination needed to provide good palliative care and by the flexibility needed to design a good program.

She and her colleagues started the program as a consult service for children who were hospitalized with complicat-

the parents to provide medical treatment, pain and symptom management, and other care at home.”

Both she and Dr. Friedrichsdorf emphasized the value of open inquiry with parents, children and families.

“Each family is unique in how they perceive illness and how they make decisions about treatment and end-of-life care,” said Dr. Nageswaran. “When we meet families, we meet them without a set agenda, and we make sure we don’t impose our structure.”

Similarly, Dr. Friedrichsdorf said, “When I enter a room, the first thing I say is, ‘How can I help you?’ We start with that open question.” At that point, he said, surveys or other structured tools can be used to help determine needs and care plans.

One of the thorns in the field of pediatric palliative care is



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**“Each family is unique in how they perceive illness and how they make decisions,” said Dr. Savithri Nageswaran.**

ed, often life-limiting conditions. The service used a half-time nurse coordinator, a one-quarter full-time equivalent (FTE) clinician post to be shared by a handful of physicians for rotating on-call duty, and a 1% FTE post for a physician coordinator.

“Very soon, we realized that the biggest need was to facilitate collaboration between multiple providers and to ensure sufficient continuity of care as these children transition back and forth from the hospital to home,” Dr. Nageswaran said in an interview. “We weren’t achieving this with the traditional consult model.”

In a subsequent restructuring, physician time was consolidated into a one-third-time FTE coordinator post, which Dr. Nageswaran fills herself, and funding was obtained from the federal Maternal and Child Health Bureau to add another half-time nurse coordinator who could focus on making home visits and coordinating home-based care in one local county.

The flexibility to coordinate care outside the hospital is critical, Dr. Nageswaran said. One of the 235 children cared for under the palliative care program thus far was a child with a rare genetic disorder characterized by skeletal abnormalities, urologic abnormalities, and severe neurologic impairment and seizures.

“The family wanted end-of-life care to be delivered at home, but they didn’t want to forgo medical care,” Dr. Nageswaran recalled. “We went step-by-step, aligning the family’s wishes with the care the child received. We worked with the primary care doctor, the subspecialists, the home health agency, and

the unavailability of hospice services for many children. Currently, most families have to forgo home-health services to receive hospice services.

Some states have taken action; policy reform passed in California in 2006, for instance, makes it easier for parents to utilize the Medi-Cal hospice benefit for children. A section of the federal Patient Protection and Affordable Care Act, moreover, is expected to change the Medicaid system to allow children with life-limiting conditions to receive both hospice care and curative treatment.

Another problem is poor provider reimbursement. “Physician services are reimbursed, but not enough to account for the amount of time involved,” said Dr. Nageswaran. “And the services of nurses and social workers, who are key to pediatric palliative care programs, are not reimbursed.”

She jump-started her program with a grant from the Duke Endowment, a private foundation, but now relies primarily on financial support from the hospital. Dr. Friedrichsdorf estimates that his hospital is reimbursed for only about half of its costs, and says that it relies heavily on philanthropy to make up the difference.

One goal in the meantime, said Dr. Berlinger, is to “influence the culture of health care so that pediatric palliative care is recognized as ethically mandatory.”

The \$15,000 awards that Dr. Nageswaran and Dr. Friedrichsdorf received were given by the Hastings Center, a bioethics research institute based in Garrison, N.Y., in partnership with the Cunniff-Dixon Foundation, a foundation that focuses on the doctor-patient relationship near the end of life. ■