

Palliative Care Initiated Earlier, Focusing on Family

BY BETSY BATES

Los Angeles Bureau

ANAHEIM, CALIF. — An evolving paradigm for the palliative care of seriously ill children centers on “family-focused comfort care” from the time of diagnosis, not just when aggressive attempts at disease eradication have failed, specialists said at a meeting sponsored by the Los Angeles Pediatric Society.

The new palliative care movement grew out of significant resistance to the hospice model of care, which, in reality, seemed to place children in one of two categories: those considered curable and receiving life-prolonging therapy, or those whose disease had progressed beyond curative options, sending them into the realm of “palliative care.”

That approach simply did not work in many cases, because physicians and families proved so reluctant to shift a child from one category to the other, the specialists said.

In pediatric oncology, where most models of palliative care evolved, the goal is a

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cure, said Dr. Gary A. Walco, director of the David Center for Children’s Pain and Palliative Care at the Hackensack (N.J.) University Medical Center.

That’s where federal resources have been focused; that’s where research has been

centered; and that’s been the mind-set for many specialists who care for children with life-threatening conditions, for the most part, he said.

“If you’re talking about helping children die, by definition that goes against a ‘good outcome,’” he said.

Nonetheless, Dr. Walco is probing the question, “What does a good death look like in childhood?” in hopes that the new model of palliation can begin to incorporate elements of his findings early in the course of treatment.

In his multicenter studies on quality of life and spirituality in terminally ill children, his accrual is “sadly pathetic.”

One patient was referred to the study 2 hours before death.

Indeed, previous research has determined that many children end up “suffering greatly” in what proves to be their last months of life because no one wants to “give up” and summon resources focused on the child’s comfort and end-of-life physical, emotional/psychosocial, and spiritual issues, said Dr. Lonnie Zeltzer, director of the pediatric pain program at the University of California, Los Angeles, Mattel Children’s Hospital.

“What parent wants to say, ‘I give up on my child?’

“The idea of not wanting to—quote—‘give up’ on children tends to push many more procedures and many more hero-

ics,” said Dr. Zeltzer, professor of pediatrics and anesthesiology at the University of California, Los Angeles.

The new model abandons the “either/or” wall between curative and palliative care, she explained, with age-appropriate quality-of-life and family issues addressed from the time of diagnosis or recognition that a child has a life-threatening or potentially life-limiting condition.

“They may not die,” she said. “They may get a transplant and be fine.”

However, children do die: More than 53,000 a year, from all causes, in the United States. There are 500,000 children diagnosed with life-limiting conditions each year and 5,000 of these children are living in their last 6 months of life right now, said Dr. Zeltzer.

More intensive communication up front has the promise of making all of these children more comfortable and having their emotional and spiritual needs, and those of their families, be a more in-

tegral part of their care. For those who do not move on to cure, difficult decisions will not come as such a shock to families, she predicted.

“As curative treatments become less and less likely [to be effective], comfort care issues become greater and greater,” she said. “It’s not just giving meds. This is where the pediatrician or primary care family physician comes in. It’s communicating with the family.”

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applied to a wider circle of children: not just those with cancer but also critically ill preemies and newborns, children with neurodegenerative diseases, and those with genetic illnesses.

The new palliative care paradigm has no place for time limits, such as the requirement in many states that a pediatric patient is not eligible for hospice care unless a physician determines he or she has 6 months or less to live.

The perils of delaying palliative care until the end were made clear by examples from Dr. Zeltzer's experience and examples cited by audience members.

Physicians told of relinquishing all con-

tact with patients to hematology/oncology or other specialty groups, only to have them referred back, abruptly, when they had just weeks to live.

Dr. Zeltzer told of adolescents and their families individually despairing over the idea of more treatment unlikely to confer benefit but reluctant to "give up" for the sake of one another.

In a system in which palliation represents the end of life, parents may not accurately convey the degree of their child's pain for fear that it could divert attention from cure or force all involved to acknowledge deterioration in the child's condition. ■



With more intense communication occurring up front, children's emotional and spiritual needs, and those of their families, become a more integral part of their care, Dr. Lonnie Zeltzer said.

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