

Shades of Black and White

Biomedical ethicists, clinicians and parents gathered at Children's third annual bioethics conference to discuss the difficult issues that arise when parents and providers disagree about medical care.



The Rev. John Paris, who served as an expert witness in the landmark biomedical cases of Karen Ann Quinlan and Baby K, discusses the right of parents to refuse treatment for their children.

“NAVIGATING CONFLICTS: WHEN PARENTS AND PROVIDERS DISAGREE ABOUT MEDICAL CARE” WAS THE TOPIC OF THE THIRD ANNUAL CONFERENCE HOSTED BY THE TREUMAN KATZ CENTER FOR PEDIATRIC BIOETHICS, THE NATION’S FIRST CENTER DEDICATED SOLELY TO THE STUDY OF ETHICAL ISSUES THAT ARISE IN PEDIATRIC HEALTH-CARE DELIVERY AND RESEARCH.

On an April morning in 1995 at the University of Arizona, Dr. Benjamin Wilfond received a frantic phone call from a young resident.

“Thank goodness you’re back on service,” said the resident. “I have very religious parents who refuse to withdraw ventilator support for their baby. They are waiting for a miracle.”

The parents’ desperation was real: Their two-week-old son, Raphael, was born with campomelic dysplasia, a lethal form of dwarfism characterized by severe breathing problems and profound intellectual disability. The condition would require him to have 24-hour-a-day assistance from a ventilator for as long as he lived.

As the attending pulmonologist, Wilfond’s task was to help the parents decide the best course of action to take for the newest member of their family.

Wilfond recounted this story to 250 physicians, nurses, social workers, ethicists, hospital administrators and parents gathered at the third annual conference of The Treuman Katz Center for Pediatric Bioethics at Children’s Hospital.

Raphael’s story — one of many thought-provoking medical cases discussed by the nation’s leading bioethicists at the two-day conference — underscores what the science of medicine cannot do: grapple with the difficult issues that surround what is in the best interests of a child and family.

No cut-and-dry answers

By the 1970s, new medical treatments and technological innovations in pediatric medicine were not only making children feel better, they were helping them get better. Yet these advances also created expectations — sometimes on the part of providers and sometimes on the part of parents — that extraordinary measures should be taken to prolong a child’s life even when death from disease or injury was imminent.

“The ‘if it can be done, it must done’ mentality is not always the best way,” says John Paris, SJ, PhD, professor of bioethics at Boston College. “Along with the value



Pediatrician Dr. Norman Fost, director of the Program in Medical Ethics at the University of Wisconsin, responds to a question about “futile” treatments.

placed on prolonging life, you have to take into account the level of the child’s suffering.”

In Raphael’s case, Wilfond gently explained the difficult options to the boy’s Spanish-speaking parents through a translator: Withdraw ventilator support and allow Raphael to die, or take Raphael home and provide 16-hour-per-day care because insurance would pay for only eight hours of daily home nursing care.

Raphael’s mother asked, “Will my son suffer if he is permanently on a ventilator?”

Wilfond responded that there was no clear answer to her question. He explained that some children were very uncomfortable on the ventilator and families had a difficult time providing care, while other children and families did quite well.

At this news, Raphael’s father clasped his hands together in prayer and gave thanks to God for providing the miracle he’d been waiting for.

Wilfond was stunned. He assumed the long-awaited miracle was a cure.

In reality, Raphael’s parents understood that a cure was not possible. Their miracle was in hearing that Raphael might not suffer on mechanical ventilation.

“That case taught me not to make assumptions,” reveals Wilfond, who now directs the Children’s bioethics center. “After working with Raphael’s parents, I started asking parents what information they needed to make the best decision for themselves, their child and other siblings.”

Communication ... and humility

For Raphael, communication helped his parents come to a mutual agreement with providers.

However, communication doesn’t help all providers and parents to agree.

Dr. Lainie Friedman Ross, director of the Ethics Consultation Services at the University of Chicago, believes that disagreements arise when providers and parents have different value judgments about medical treatments or do not assess the probability of risk to a child in the same way.

In her pediatrics practice, Ross has had parents refuse to allow their children to be vaccinated for measles out of fear that the vaccine may cause brain damage.

“I respond to their concerns by providing information and asking them to think about the risks to which they are unwittingly exposing their children,” says Ross. “The risk of brain damage from the measles vaccine is one in one million, whereas the risk of brain damage from getting measles is 1,000 times greater.”

Ross advocates listening to parents’ concerns, educating them about the risks and benefits to the child and not severing the relationship if a parent goes against the provider’s recommendations.

“As physicians we must look long and hard before we call any parental refusal of diagnostic testing or treatment ‘abuse or neglect.’ Parents should have the right to make decisions for their child,” says Ross. “Only in the rarest of circumstances,

when a child is in jeopardy, should we override a parent’s decision, and then we need to do so with humility.”

As today’s technologically complex medicine continues to spur ethical debates in pediatrics, one thing is for certain: Both providers and parents will be part of the discussion.

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The annual conference provides a forum for clinicians, ethicists, hospital administrators and parents to explore ethical issues in pediatric health care.

View this year’s conference presentations at http://bioethics.seattlechildrens.org/events/pediatric_bioethics_conference/agenda.asp