

Choosing Comfort Care is Just the Beginning

The Gold Foundation *Ethics for Lunch Seminar Series*: Difficult Cases from the CHONY Ethics Committee.

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John Lorenz, MD, Chair
Morgan-Stanley Children's Hospital of New York-Presbyterian Ethics Committee.
Thursday, 22 March 2007
12:00 noon - 1:30 pm
Columbia University Medical Center
Hammer Health Sciences Center

Dr. John Lorenz, Chair of the Ethics Committee, presented the poignant case of Charlie, a seven-week old infant brought into the Emergency Room with what his mother thought at the time was a normal febrile illness. Testing confirmed the illness to be Wolman's Disease, a lethal condition that usually claims its victims in the first year of life. Outside of being treated symptomatically and with a low cholesterol diet, there were few options open to treat him, as he was considered to be a poor candidate for a Bone Marrow Transplant which would not have improved his prognosis anyway.

Given that there was no definitive treatment, the parents, who came from Australia, opted for comfort care, little realizing what anguish they and their son would come to endure. On the 23rd day of Charlie's hospital stay the parents, in an unusual action, requested an ethics consultation. They had repeatedly requested that the narcotic dose be increased to manage their son's evident pain, while acknowledging the risk of death due to respiratory depression. However, the CHONY Pain Service judged Charlie's pain to be effectively controlled without an increase in pain medication.

The parents had three questions for the Ethics Consult:

- How and who should judge Charlie's quality of life? How can you determine pain level in an infant?
- What is the difference between withholding life-sustaining treatment and ending life? Is the latter permissible?
- Who has the primary responsibility and authority for decisions about their son's health care?

Clearly, Dr. Lorenz said, the reality of Charlie's experience of "comfort care" turned out to be quite different from his parents' expectations. They had expected a gradual, natural decline to death instead of the up and down course their son

endured. They expected Charlie would have no pain but learned that his comfort level changed from day to day, often seeming extreme. They learned that pain management is an inexact science, particularly with an infant who cannot fully communicate his feelings. The parents expected their decision to provide comfort care for their son to be cathartic for them, but instead it only made them feel worse, a kind of “gnawing at the heart.”

The parents had anticipated that Charlie might be given a dose of medicine to end his life and suffering peacefully, only to be greatly disturbed to witness him deteriorate mentally and physically. They felt helpless, but still somewhere in the back of their mind held out hope for Charlie’s survival and a normal life. They were fearful about the manner of his death – would it be peaceful, or would there be a massive fatal hemorrhage? And finally, they were having difficulty coping with the duration of their son’s decline – the uncertainty of how long he might survive and what his quality of life would be.

On the 26th day of his hospital stay, Charlie died. Dr. Lorenz asked ‘Is there such a thing as a good death, especially in pediatrics?’ Despite their questions and concerns about his pain management, Charlie’s parents had a very good relationship with their son’s medical team and invited them to the memorial service they held for him in Central Park. Things were not perfect, Dr. Lorenz said, but it was not for lack of caring.