

## *Virtual Mentor*

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### **CASE AND COMMENTARY**

#### **Palliative Care for an Infant with Short Bowel Syndrome and Advanced Liver Disease, Commentary 1**

Commentary by Mark Sheldon, PhD

#### **Case**

After 5 months of routine NICU Care, and treatment for malabsorption and malnutrition, Mary was discharged from the NICU and allowed to go home with her parents. Eight hours after discharge, her parents brought her back to the hospital with fever and vomiting. During this second hospitalization, Mary had bacterial and fungal infections, multiple changes in her vascular access sites, and complications, including advanced liver disease, from the total parenteral nutrition (TPN). Her liver dysfunction was characterized by abnormal coagulation, only partially corrected by blood products and vitamin K, hypoalbuminemia, and hypoproteinemia. She bled from her nose and mouth after crying or sneezing, and extensively from her ostomy site. Mary had multiple episodes of hypovolemic shock that required blood transfusions. Her massive hepatosplenomegaly interfered with respiration.

Early in her NICU stay Mary's physicians discussed with the Janes the possibility of transporting Mary to another medical center for an intestinal transplant. Mary's parents appeared to understand the seriousness of their daughter's condition and wanted the doctors to do "everything possible" for her. Mary's liver dysfunction progressed and she became more edematous, had skin breakdown, and had to be more frequently volume resuscitated and transfused. Her tenuous condition now made it impossible to consider moving her to another location for a transplant. Mary's physicians considered her condition terminal and could see that she was suffering.

Dr. Andrews and her colleagues tried to talk to the Janes about palliative care and the imminent death of their daughter. In one instance Dr. Andrews approached Mrs. Jane, who never left the hospital unless her husband or mother came to relieve her, but Mrs. Jane stopped Dr. Andrews in mid-sentence.

"I see where you're going with this, Dr. Andrews, but my baby is strong. Children are resilient. Mary got well enough to go home once and she'll do it again, we've just got to give her a little time."

\*The patient's name has been changed to protect her privacy and that of her parents.

## **Commentary 1**

This is a case where it is important for Dr. Andrews to remember 2 things: who the patient is and the Hippocratic Oath. The patient is Mary Jane and the Hippocratic Oath states, "...I will keep them [patients] from harm."

It is particularly difficult to remember who the patient is when the patient is a child and there are loving parents involved. Psychologists indicate that there is hardly an experience more painful and traumatic than the loss of a child. Parents clearly and reasonably expect to die before their children; a child's death goes against the natural order. The essential role of parent is to protect the child. Furthermore, if the physician is a parent, he or she may identify too strongly with the parents, or may feel guilt in connection with the fact that his or her own child is healthy while the patient is dying. All of this means that the tendency of the physician will be to continue to treat as long as there are treatment alternatives to pursue.

Much has been written about the importance of recognizing that the family is often centrally involved in the treatment of any patient and may be even more involved in the cases of pediatric patients. No one would take issue with a concern to accommodate the wishes of the family to the extent possible. For physicians and staff the hospital world is routine, and they may not always appreciate the challenges families confront when a loved one is hospitalized. Given the extent to which the treatment of illness and disease is so completely institutionalized in our society, however, it is not unusual for families to face, for the first time and all at once, 3 very significant challenges: an exceedingly technologically complex and unfamiliar environment, an experience of great emotional and psychological complexity, and enormous personal responsibility. And it is the task of the physician and staff to educate the family in regard to all 3 and to help the family cope.

The neonatal unit, particularly, is a place of great technological complexity. The case description makes clear that everything has been done for this baby. One imagines that the parents have been engaged in a huge effort to understand the options that the technology has made available for the treatment of their baby, although it is not clear that they have fully appreciated the cost to their baby of such efforts. Considering their baby's pain and suffering, one is not able to imagine the emotional and psychological anguish that the Janes have experienced. It is likely that nothing in their previous lives prepared them for the profound responsibility that they are being asked to shoulder.

Another feature of this case, which Dr. Andrews should take into account, is that the neonatal unit is a place that requires a team effort. Nurses have been involved fundamentally in the care of this infant, probably at great emotional cost to them. As the baby's skin breaks down, they, more than anyone, are aware of what the baby must endure if additional life-saving interventions are undertaken. The physician is accountable to her staff, as well as the parents, and the conscientious staff takes the imperative to do no harm just as seriously as do the physicians.

True, much is remarked about the resilience of children. Pediatricians are often surprised when a child pulls through. But it is clear that there are cases where such an outcome will not be possible, and this is one of those cases. This case has involved the pursuit, by clinicians, of every available heroic intervention that might provide benefit. However, the issue, at every step of the way, has been whether any benefit could be achieved that would outweigh the burden, the discomfort, and the suffering to which the baby was subjected as these interventions were undertaken.

At this point, it is clear that no further benefit can be provided, all options have been exhausted, and the baby stands only to experience more suffering and pain. Furthermore, she will die regardless of what is done. This is the time for Dr. Andrews to bring her professional judgment to bear. This is what being trained to exercise professional judgment is all about. Gently and firmly, she must refuse any interventions that aim at prolonging the baby's life. She must say "no" to the parents and explain that, ultimately, the baby is her patient, her responsibility, and that her professional ethic requires her to refuse to intervene aggressively to prolong this baby's suffering. It is time, she must explain, to shift entirely to palliative care in an effort to keep the baby comfortable and allow her to die. If the parents refuse, she must tell the parents that she can no longer care for this baby, that what they are asking her and her staff to do constitutes a harm that is not acceptable.

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*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.*

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