



Charles L.
Stewart, FACHE

Making Decisions about Neonatal Life Support

Respecting the views of all concerned requires coordinated communication among all parties.

Q. *My hospital's Ethics Committee met with our staff neonatologists to discuss discontinuing advanced life support for a two-month-old infant born with severe physical abnormalities. The parents of the baby agreed with the physicians and the committee's recommendation. However, the nurses involved in caring for the infant disagreed with the recommendation and refused to follow the wishes of the parents. How can I resolve this issue in a manner that respects everyone's views?*

A. A few years ago I experienced a very similar situation to the one you describe. Dealing with withdrawal of life support, particularly when it involves an infant, can be one of the most emotionally challenging ethical dilemmas that a hospital leader can face. In our example, a meeting of the Ethics Committee was called at the request of the staff neonatologists. The neonatologists recommended discontinuance of advanced life support for an infant with severe physical abnormalities who had been a patient in the neonatal intensive care unit for several weeks. The parents of the infant attended the committee meeting and expressed their desire to follow the neonatologists' recommendation. After a discussion and an assessment of the facts, the

committee approved the recommendation, and the neonatal intensive care unit nurses were informed of the parents' decision. The nurses who had been involved in the care of the infant since her birth questioned the parents' wishes and the committee's decision. The nurses communicated to their nurse manager that they refused to participate in caring for the infant during her death. My initial reaction was "How could they refuse to follow the parents' request?" As administrator, it was my responsibility to honor the wishes of the infant's parents while respecting the moral and ethical dilemma the nurses faced and to somehow bring about a resolution that respected everyone's views.

I called a second meeting of the Ethics Committee and invited the nurses who were involved with the baby's care in the NICU. Five of the nurses who had provided care for the infant attended the meeting. I explained that the purpose of the meeting was not to make a decision about the fate of the baby but to open lines of communication between all parties. The nurses expressed that they did not feel they had been completely informed of the seriousness of the baby's condition. They did not believe that the parents had shown

proper concern for the infant, as evidenced by the small amount of time that they had spent with the baby in the NICU. It was their belief that if the parents had really cared about the infant, they would have requested the baby be transferred to the regional children's hospital for additional evaluation and treatment.

The neonatologists explained the seriousness of the infant's condition to the nurses. They explained that because of difficulty with the lungs and abnormalities of facial structures, the infant's ability to breathe was impaired, and all attempts to remove her from a ventilator had failed. EEG activity had been abnormal at birth, and a report by a pediatric neurologist consulting on the case indicated uncertainties of the infant's potential intelligence and that quality of life was very unpredictable. The neonatologists explained that, in their opinion, the baby was suffering. They had discussed the seriousness of the condition with the parents as well as the option of transfer to another facility. The mother did not want to put the baby through more test procedures or suffering when there was so little hope for improvement. The father's main concern was the quality of life for the infant.

The director of Social Work explained that she had counseled the parents during the baby's hospitalization. She had observed that the baby's condition had been very difficult for the parents. Initially, the parents had spent a great deal of time at the hospital, but as time went by the parents had visited less frequently. The social worker explained that, in her opinion, what had appeared to be a lack of concern on the part of the par-

ents was actually their defense mechanism for avoiding hurt and further attachment to the infant. The parents were young and unmarried and held low-paying jobs. The social worker was initially concerned with the amount of time the parents were spending with the infant; however, she had come to believe they deeply cared for the baby but were emotionally torn between being with the infant and needing to maintain their income.

The attorney informed the committee that state law was clear that an adult has the right to make medical decisions for himself or herself, but it was not clear as to what parents or other responsible parties can or cannot do in a situation such as this. The attorney expressed that there was no legal reason not to follow the parents' wishes. The social worker explained that she had initially questioned the parents' ability to make a proper decision and that she had contacted the state's Department of Human Resources to assume state guardianship of the infant. The state department had refused to get involved.

It became abundantly obvious that our well-intentioned structure designed to address this type of issue had been seriously compromised by a lack of coordinated communication between all parties. Those who had been most intimately involved in the care of the patient—the nurses—were the least aware of most of the facts. I complimented the nurses for their compassion and commitment to their patient. I agreed with their suggestion that we should seek a second opinion and agreed that the hospital should bear the expense. I believed this was necessary to achieve consensus among the

family, committee members, and nursing staff. A second opinion was obtained at the regional children's hospital, but it revealed no new information. The baby was transferred back to our hospital, where the nurses then accepted the condition.

As hospital leaders, we have a responsibility to our organization to learn from our mistakes. In our attempt to resolve the issue in a manner that respected everyone's view, we identified three areas that needed improvement:

1. Communication—When the nurses met with the committee, we learned that the neonatologists had not communicated the condition of the infant to the nurses, creating a false expectation among them. The social worker had come to understand the family dynamics but had not shared this information with the nurses. Team conferences were instituted to overcome the communication barriers between nurses, neonatologists, and social workers. The Ethics Committee composition was changed to include direct caregivers of the patient whenever necessary.

2. Policies and procedures—Policies and procedures are the guides that staff look to when problems arise. When faced with the dilemma, we realized that our policies and procedures fell short as to the rights of minors and parents. Even state law offered no clear direction. It also highlighted the need to review the rights and responsibilities of employees.

3. Education—The need for greater awareness of cultural differences was made evident by the nurses' perception of the parents' behavior. Their initial refusal to participate in allowing

the baby to die was insensitive to the parents' feelings and wishes. To better prepare the nurses to deal with their emotions and personal differences, we utilized counselors to provide training in conflict management and diversity. Open dialogue about diversity can help staff be better prepared when faced with a real event. ▲

Charles L. Stewart, FACHE, is administrator of Northport (AL) Medical Center, and executive vice president, DCH Health System.

Northport Medical Center
2700 Hospital Dr.
Northport, AL 35476
(205) 333-4515
cstewart@dchsystem.com

HEALTHCARE

NEWARK COMMUNITY HEALTH CENTERS, INC., FQHC,

a community-based health and social services organization in the greater Newark, NJ area, seeks a dynamic corporate leader. With a budget of \$13 million and 150 employees, we provide comprehensive primary and preventive health care and social services to the underserved. We currently operate 6 centers with plans to open a 7th facility in early 2005.

PRESIDENT / CEO

Requirements: 6-8 years executive experience in urban healthcare management; strong fiscal/strategic planning/development skills; ability to interact effectively with BOD, government officials, funders, and community leaders. Master's degree in non-profit or healthcare administration (MBA, Medicine, Dentistry, or Mental Health degree a plus). Bachelor's degree considered based on background and experience.

Please send a resume and cover letter with salary requirements to:

Human Resources,
E-mail: careers@nchcfqhc.org
or fax to: **973-483-8281**.

EOE/AA-M/F/D/V