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Tough Decisions for Premature Triplets

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When infants are born at the borderline of viability, doctors and parents have to make tough decisions about whether to institute intensive care or provide only palliative care. Often, these decisions are made in moments of profound emotional turmoil, and parents receive different information from different health professionals. Communication can become garbled. It may be difficult to tell when and whether the patient's clinical condition has changed enough so that certain choices that had once been permissible become impermissible. In this "Ethics Rounds," we present a case of triplets born at the borderline of viability. We sought comments from the triplets' parents, the doctors and ethicist who were caring for the infants, and a bioethicist/neonatologist from another hospital.

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THE CASE

At 23 weeks 2 days of gestation, a 37-year-old mother expecting non-in vitro fertilization triplets presented at a regional hospital with preterm labor, bulging membranes, and suspected chorioamnionitis. Earlier in the pregnancy, the mother's specialist informed the parents that if the infants were born before 26 weeks' gestation they likely would not survive at that facility. On the basis of this information, the parents decided they would not

have the infants resuscitated if they were delivered before 26 weeks.

Upon arrival at the hospital, the neonatology team offered to resuscitate the infants at birth. Confronted with this unexpected choice, the parents asked that their infants be resuscitated using "reasonable but not heroic measures."

At birth, Baby Anna weighed 1.5 pounds, Baby Henry weighed 1.8 pounds, and Baby Cohen weighed 1.4 pounds. All the infants responded appropriately to brief resuscitative efforts in the delivery room. The parents consented to transfer to a tertiary care facility.

Anna's head ultrasound revealed a unilateral grade IV intraventricular hemorrhage (IVH). After discussion of prognosis, the parents asked to have her extubated and to provide her with comfort care. Anna died at 22 hours of life. Henry had significant hypotension requiring multiple saline boluses and was then started on pressor support. Head ultrasounds at 12 and 36 hours of age were normal. At 18 hours of age, Henry developed a tension pneumothorax. The care team planned to place a chest tube, but the

abstract

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family did not want “heroic measures” taken. A needle decompression was performed and resolved the condition. His condition improved overnight, and he was weaned to minimal oscillator settings with minimal fraction of inspired O₂ requirement, his pressor support was discontinued, and his vital signs were stable. Cohen also had some hypotension requiring pressor support, which he was weaned off by 36 hours. Head ultrasounds at 12 and 36 hours of age were both normal. At 36 hours of life, the parents asked that both infants be extubated and that treatment to be redirected to comfort care. Some members of the clinical team were uncomfortable with the decision to redirect to comfort care at this point because the infants were stable and doing reasonably well. An ethics consult was called.

THE PARENTS, EMILY AND SCOTT, COMMENT:

When we first found out we were pregnant, we were thrilled. We had a happy family—the 2 of us and our 3-year-old son, Scotty. We were excited to be blessed with a spontaneous triplet pregnancy. We picked out names for the triplets—Anna, Henry, and Cohen.

The pregnancy was very difficult. I (Emily) was having multiple symptoms, all of which the specialist explained as normal in a triplet pregnancy, including dizziness, bloody nose, joint pain, severe nausea, loss of appetite, malaise, and heart pain (“from pumping extra blood”). My ob-gyn, whom I’d known for years, had put me on bedrest and medical leave. He then transferred my care to a specialist of maternal and fetal medicine.

At ~17 weeks, the specialist told me that “sludge” was forming in Anna’s sac and that there was “beaking” of the cervix. The infants weren’t moving much. I was told that “there wasn’t room.” At 19 weeks, more beaking and sludge was evident. I had

severe pain on physical examination. The specialist didn’t know if this was from an infection. No oral or vaginal cultures were taken. No complete blood counts were drawn. No susceptibility tests were done. At 21 weeks, the specialist prescribed tocolytics without checking for infection.

At 23 weeks, the specialist was out of town. My blood pressure was even lower than it had been, and I felt ill and lethargic. My heart rate was ~150, and my white blood cell count was elevated at 22 000. Each baby’s heart rate was >165. My cervix was dilated to 1 cm. My water broke. An emergency cesarean delivery was performed. The doctors noticed signs of chorioamnionitis.

Previously, it was explained to us that should our triplets be born sooner than 26 weeks, our facility was not equipped to nurture them. The night they were born, a neonatologist told us that survival was possible at 23 weeks if transferred. The attending ob-gyn explained that the likelihood of neonatal death was 80% and that many infants who survived had neurologic problems.

With our consent, our triplets would be transferred to a tertiary care center where 23 weeks’ gestation was considered “viable.” The infants were transferred to a referral center to have a chance at living. We were relieved to know that they would have a chance to live. Without the neonatologist’s presence that night, our infants would have been handed to us dead.

The next morning, I was diagnosed with an infection of the uterus that entered my abdominal cavity. My white count was 31 000. My intestines shut down. We now realized that an unknown microbe had been in my uterus with the infants. Now it had spread into my abdominal cavity.

While I was getting sicker, so were the infants. We heard about them on

the phone. Once we were informed that Anna had suffered a level IV brain hemorrhage and comfort care was recommended, our thoughts progressed to “what was next”? Cohen’s blood glucose was off the charts and not stabilizing. He developed a pneumothorax, which was described to us as the lungs’ inability to expand and deflate for proper breathing, trapping air in the chest cavity and putting pressure on the heart, lungs, and other organs. Henry already had a pneumothorax aspirated by needle. We were told that he was “stable” but also that he had developed a second pneumothorax. We were told Henry had “absent bowel sounds.” We got mixed messages. The infants were bigger than expected, which increased their chances for survival. And they were somewhat stable. But Scott and I had horrible, gut-wrenching feelings that the infection in my uterus had infected them. We were convinced that the outcome was not promising. I just knew that they had been sick inside me the entire pregnancy.

We were told that they could not be comforted, that a simple touch would not have soothed them but would, instead, cause pain. We knew that they could not see because their eyelids were still fused shut. We could only imagine the fear inside them as they felt, heard, and experienced lights and shadows in a world in which they were not yet meant. We felt selfish. We felt scared for them. We worried that treatment would only lead to a drawn-out and painful death for the boys. We felt that allowing their spirits to go on to Heaven was our only option.

I asked if we could just pull the ventilators and allow them to go. I asked Scott if that was OK, and he felt the same. We never imagined, ever, that we could make such a decision. Immense sadness and peace came over me. I wanted them to

experience, once, what it was like to not suffer.

THE NICU CARE TEAM COMMENTS:

Infants born at 23 weeks remain in the gray zone of clinical treatment options and outcomes. Given the clinical uncertainty about outcomes for infants born at this gestational age, we generally allow parents to decide whether to resuscitate at birth and provide life support. If the parents had chosen not to resuscitate their infants at birth or declined to transfer them, we, the NICU care team, would have been comfortable with those decisions. However, once the infants arrived in our NICU, we were conflicted over how best to respect the parents' wishes and fulfill our obligations to the infants.

Anna's prognosis and treatment options were more straightforward than those of her brothers. When a grade IV IVH was discovered at 18 hours of life, we had more definitive information to discuss with the parents about Anna's likely prognosis. We discussed options on the phone with her parents, and when the parents chose to redirect care, we all fully supported that decision.

However, Cohen's and Henry's situations presented a more difficult decision for the clinical team. The difficulty for us was that, at the moment of the request to redirect care, both infants were relatively stable. We knew that adverse events would likely occur during the course of their NICU stay. We also knew that their ultimate outcomes were unpredictable. The most widely used prognostic estimator considers only data that are available at the time of birth. We did not feel that such data were completely reliable for these particular infants at 36 hours of age.

We debated how to proceed. We understood that the parents have the right to make health care

decisions for their infants. We also knew that this right is limited by a legal obligation to do what is best for infants. We felt an obligation to advocate for the infants. But should we go to court to remove the parents' right to make this decision? Should we try to convince them to change their minds, and if so, when do continued conversations to change their minds become bullying and coercive? At this point, the mother was ill and on intravenous antibiotics, and the father was understandably distraught over the fact that almost everyone in his family was in a critical medical situation.

We had multiple in-depth conversations with the parents regarding what was in the best interests of the infants. The parents explained that their decision was not rushed and that it reflected things that they had carefully considered ever since they learned how precarious a triplet pregnancy could be. They were knowledgeable about the possible outcomes for their infants. They told us of significant life experiences that informed their ideas about quality of life. Their decision to redirect care seemed to have been made with great care and consideration and reflected what both parents and their extended family believed was in the best interests of the family, including Henry and Cohen.

Ultimately, we decided against going to court. The parents' decision, although one that not all of us would have made, was consistent with clinical and ethical norms regarding the best interests of Henry and Cohen. We did not want to bully the parents into a decision they did not want.

MARK R. MERCURIO, MD, MA, COMMENTS:

This case involves the right of parents to make an informed decision on behalf of their critically ill

child. Sound decision-making should be based on good data. These parents may have begun their decision-making process with misleading information. They were told that the infants "likely would not survive" if born before 26 weeks. In fact, by 25 weeks, a female triplet would have at least a 50% chance of survival. Had Anna not suffered grade IV IVH and had she received antenatal steroids and mechanical ventilation, her predicted chance of survival even if born at 23 weeks, would have been ~1 in 2, a bit lower than for her brothers. Also, it is not mentioned how the obstetrical estimate of gestational age was determined in this non-in vitro fertilization triplet pregnancy. Depending on the timing of the first ultrasound, dating could be off by as much as 2 weeks, and this uncertainty (and thus the wide range of potential outcomes) should be shared with parents as they consider attempted resuscitation. In this circumstance, the postnatal assessment was congruent with estimated gestational age.

The initial parental decision not to resuscitate before 26 weeks, if based on misleading or incomplete information, was not a truly informed decision. It could rightly be argued that an optimal sharing of information is not possible in this setting, but that does not relieve the obligation to provide at least adequate information. The parents' decision not to attempt resuscitation was reversed, but nevertheless, the initial information may well continue to influence their thinking. Moreover, they reportedly requested "reasonable but not heroic measures." Heroic measures is not a term typically initiated by parents, and that request, or the wording of that request, was more likely based on wording initially used by the medical team when discussing options with the parents. It is an unfortunate term and should be avoided, because heroic means 1 thing to

1 person and perhaps something different to someone else. A chest tube might seem more heroic than a ventilator to some but not others, for example. This adds to concerns about the appropriate presentation of information on which they are basing their decisions. The doctors and the ethics committee should explore the parents' understanding of the current prognosis and of the risks and benefits of various possible interventions.

Even accurate outcome data can be misleading. It is a common mistake to quote reported overall survival statistics for a given gestational age, rather than survival among those for whom resuscitation and intensive care had been provided. This risks underestimating the chance of survival when counseling parents about resuscitation, in particular at a gestational age wherein resuscitation is often forgone. Furthermore, the likelihood of moderate or severe neurodevelopmental impairment is often overestimated in counseling by using follow-up data at 18 to 22 months (eg, the Eunice Kennedy Shriver National Institute of Child Health and Human Development outcome estimator); disability rates are significantly lower when examined at 4 to 8 years. It could reasonably be estimated that, at the time of birth, Henry and Cohen had an ~20% chance of survival with a substantial chance of neurodevelopmental impairment in the event of survival.

With a prognosis of this magnitude, it is common in the United States and many other nations for parents to be given a choice regarding resuscitation at 23 weeks. Ideally, parental decisions should be based primarily on considerations of the patient's best interests, determined by weighing potential benefits and burdens to the child of intervention in question. In this situation, the parents' right to refuse life-sustaining medical treatment (LSMT) is justified

by the poor prognosis and the burdens of treatment.

If one agrees the parents should have been given the option to decline LSMT at the outset, then they should continue to have that option unless new information has come to light that significantly alters the prognosis. It is encouraging that the boys have survived the first 36 hours. Information obtained since birth for Cohen and Henry is on 1 hand reassuring (normal head ultrasound) and on the other hand worrisome (hypotension, hypoglycemia, tension pneumothorax). The prognosis for each of these patients may well be different than what one would have thought at the time of delivery but not different enough to negate their parents' right to decide. If there were convincing data that a patient's prognosis had become dramatically better, then it could reach a threshold beyond which ongoing LSMT becomes clearly in his best interest, and thus obligatory. For these 2 boys, the level of ambiguity regarding their best interests remains such that the parental right to decide should be honored.

The clinical team should be commended for consulting the ethics committee. The views of individuals removed from the situation, with training and experience in clinical ethics, often prove helpful to all involved. The ethics committee should ensure that the parents are making a truly informed decision, are competent decision-makers, and are acting in good faith with each child's interests in mind. The relevant data and the potential benefits and burdens of all feasible options, including delaying the decision to withdraw LSMT, should be reviewed. The members of the staff who are uncomfortable should be heard. It is understandable for them to have misgivings, given the change of plan, and the improved status of the patients. Withdrawal of LSMT is morally equivalent to withholding,

but it often feels different to the staff and family. Their discomfort should be discussed in an open and nonjudgmental fashion.

On the basis of the information provided for this case, the ethics consultant should recommend that the clinical team honor an informed parental decision for comfort measures only for both patients.

EMILY AND SCOTT COMMENT:

We heard over the phone that life support had been stopped and that the boys were dead. When the calls came in, I was physically unable to answer the phone, so Scott did this, and it took a toll on him. Our infants were gone. Nothing could have prepared us.

After our infants passed, I remained hospitalized for a week, receiving amoxicillin, clindamycin, ampicillin, gentamicin, and vancomycin. The uterine infection had spread throughout my body. I was told that my chances of survival were just 50/50. At that time, the infectious disease physician confirmed resistant Strep B infection of the uterus and diagnosed/treated for an anaerobic infection as well. She transferred me to another hospital to facilitate my recovery. Progress was made but also pain beyond compare.

For months I have searched and researched to be "certain" we made the best decision for our infants. We were not there to hold them when they passed. We thought it was more important for them to go as soon as possible, not to selfishly have them suffer longer to wait on our presence. They had skilled calm hands to transition them, and in our mind, "now" was the best time before another medical procedure was necessary; before more blood transfusions were done; before another finger prick or another radiograph was taken; before they had a chance of getting diaper rash;

before their skin broke down further; before they had a chance to get worse; before they had a chance to get better.

We are thankful for all the help we received for their little lives and for their passing as well. Our neonatologist has been crucial for our family's understanding and acceptance. The chaplain blessed them before passing. A thoughtful nurse took pictures of them for us, which has truly helped with our healing. It is difficult to heal when you cannot visualize your own children's faces. Now we can, in our cherished memory book. Anna's feet look like mine. Henry's and Cohen's feet look like Scott's and Scotty's.

At Anna, Henry, and Cohen's funeral, we took turns reading them *Good Night*, we placed their good-bye

treasures under their crocheted white blankie, said our prayers, and said our goodbyes. It was hard to believe how tiny they were, all 3 together, side by side, Henry, Anna, and Cohen sleeping peacefully. It was hard to leave. It will be a "forever" process, we do believe.

JOHN D. LANTOS COMMENTS:

One definition of a clinical ethical dilemma is a situation in which every choice is wrong. In such situations, choices may be wrong in different ways. In most such cases, there is not an intractable disagreement. Instead, well-meaning people are confused or uncertain about the diagnosis or the prognosis. This, then, may lead to sincere disagreements among well meaning parents and professionals about what is best for

patients and families. Usually, these disagreements lead to discussions in which everyone comes to an agreement. Sometimes, an ethics consultant can facilitate these discussions. As in this case, the resolution of the most pressing dilemma does not mean that tragedy has been averted or that the individuals involved do not live with an irreducible sadness. Sometimes, the best we can hope for is that, as a result of such discussions, everybody has a better understanding of all the available options and the implications of 1 choice or another.

ABBREVIATIONS

IVH: intraventricular hemorrhage
LSMT: life-sustaining medical treatment

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