


II. Dilemmas at the Beginning of Life: Biomedical Ethics in the Newborn

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INTRODUCTION

This is the second of three articles that highlight the ethical and legal issues attendant in premature neonates. We present a hypothetical case in which the parents demand aggressive treatment for their borderline viable newborn, against the medical advice of the health care team. The narrative reveals the ethical conflicts that can arise, and presents options for resolving them.

CASE PRESENTATION

John and Mary Bradley were ecstatic when they learned that Mary was pregnant with twins. Mary's pregnancy progressed uneventfully. Her weight gain was appropriate, her blood pressure was normal, and serial ultrasounds reassured the Bradleys that both fetuses were growing as expected. But, as she entered her twenty-first week of pregnancy, Mary began to have painless vaginal bleeding, and her cervix started to dilate; she was in danger of a spontaneous miscarriage. She was admitted to the hospital, placed on bed rest, and received tocolytics to slow or stop the contractions. The Bradleys, from the outset, had anticipated an early delivery, but not this early. They were aware that with today's technological advances, the perceived limit of viability outside the womb was approximately 23 weeks gestation, although there have been a few reports of infants surviving at 22 weeks gestation.

Mary remained hospitalized with intermittent contractions and bleeding. During this time, the Bradleys educated themselves on premature neonates and their likelihood of survival, as well as their common diagnoses and complications. They even located a website that provides an estimate of survival with and without severe impairment based on several perinatal factors such as gestational age, gender, and weight. The Bradleys also decided on names for their twins: Andy and Annie.

At 23 weeks gestation, Mrs. Bradley received a series of steroid injections to enhance the maturation of Andy and Annie. But, two days later, her membranes ruptured; the babies would be arriving shortly.

After Mary's membranes ruptured, Andy, who no longer had amniotic fluid surrounding him, began showing signs of distress. The Bradleys had to make a choice: emergency Caesarean section to give Andy a chance of surviving, or allowing nature to take its course. An emergency Caesarean section would place Annie at risk by delivering her at a borderline viable stage, but if the Bradleys declined the emergency Caesarean section, Andy would have little hope for survival. The Bradleys decided to go forward with the emergency Caesarean section because they could not give up on one of their babies.

Unfortunately, by twelve hours of age, Andy developed an infection and required increased respiratory support. He later became bradycardic, and despite insertion of a chest tube to evacuate free air in his chest, Andy developed seizures and died at 18 hours of age. The Bradleys, distraught, nonetheless turned their attention to Annie to ensure they would not lose another child. The Bradleys knew that for a newborn at 23 weeks gestation weighing 500 grams, the chance of death or profound neurodevelopmental impairment was 80%. The chance of survival without moderate or severe neurodevelopmental impairment was 11%. With this information, the Bradleys decided everything had to be done because they could not bear to lose another child and they did not want to later regret having done nothing to save Annie.

After two weeks of promising news about Annie's progress, her abdomen became red and distended. An X-ray demonstrated the presence of pneumotosis intestinalis, diagnostic of necrotizing entercolitics (NEC). The pediatric surgeon recommended a laparotomy and possible bowel resection with the formation of an ostomy.

At laparotomy, the surgeon found the majority of the gastrointestinal tract was affected by NEC and there was insufficient healthy bowel to salvage. The surgeon reluctantly closed

the abdomen without further intervention. The health care team described Annie's condition to the Bradleys and recommended a course of palliative care with no further aggressive intervention. The Bradleys were resolute in their determination to do everything possible to save Annie. Annie's condition continued to deteriorate, requiring increased ventilator support, platelet and red blood cell transfusions, and the need for vasopressors. Still, the Bradleys continued to demand everything be done to keep Annie alive.

Annie ultimately began showing signs of discomfort. The health care team knew the small doses of pain medication were insufficient to comfort Annie, but they could not increase the dosage because doing so would compromise her blood pressure and cause other sequelae. At this point, the health care team questioned the decisions of the parents and wrestled with the ethical issues to continue aggressive treatment at a time when Annie was showing signs of increasing discomfort and diminishing likelihood of survival.

THE ETHICAL ISSUES

Despite contrary medical advice and discouraging statistics for Annie's survival, the Bradleys are adamant that the health care team do everything possible to keep Annie alive at all costs. This conflict between the health care team's recommended course of treatment and the parents' demands raises many ethical concerns. Of the four foundational ethical principles discussed in our first article,[1] the principles of beneficence and autonomy are most relevant to Annie's case. The principle of beneficence is reflected in the physician's obligation to "do no harm," and the principle of autonomy is reflected in the Bradleys' authority to make medical decisions for Annie. The health care team and the Bradleys must wrestle with the conflict between treatment of Annie that may cause intolerable suffering and respecting the authority of the Bradleys to make medical decisions for Annie.

Physicians have both an ethical obligation and professional obligation to "do no harm". In Annie's case, at what point does continued aggressive treatment cause Annie to suffer unnecessarily with no realistic benefit? Do the physicians have an obligation to cease treating Annie aggressively knowing that treatment is intolerable despite the Bradleys' vocal calls for continued treatment? Can the parents force the physician to provide care that the physician believes is inappropriate? Evaluation of this principle is further complicated when the parents demand aggressive treatment from the outset. Parents who make such demands may perceive it to be more difficult to withdraw care later because it forces them at some point to decide that continued care is unnecessary. This leads them down a slippery slope: the parents have done everything possible so far, why stop now? The difficulty with this policy of all-out care is identifying the line is between – on the one hand – too aggressive and inappropriate treatment that harms the newborn, and – on the other – appropriately aggressive treatment that may benefit the newborn. Of course, this line is fluid and is unlikely to be readily apparent to the parents or the health care team.

THE LEGAL PERSPECTIVE

State law recognizes the authority of parents to make medical decisions for their children. And, as newborns are unable to express their wishes or desires regarding medical care, the health care team must rely on the parents to make those decisions. In essence, the parents are substitute decision makers, much like a spouse or adult child is a substitute decision maker for an incapacitated adult. The role of the substitute decision maker is to make medical decisions based on what he or she believes the incapacitated adult would want; not to make medical decisions that the substitute decision maker would want. In effect, with a substitute decision maker, it is as if the incapacitated adult is consenting to medical treatment. However, in the case of a newborn who cannot and has not expressed his or her wishes regarding medical treatment, the traditional role of the substitute decision maker is not readily applicable. Consciously or not, the parents make decisions based on what they want, which may not be in the best interest of the newborn.

The Bradleys, having already lost one child and being on the verge of losing a second child, may have judgment that is impaired to such a degree that they are unable to evaluate the harm and consequences of continued aggressive treatment. The health care team must be cognizant of the Bradleys' emotional state, yet must also advocate on behalf of Annie to address her discomfort. Maintaining this balance between respecting the Bradleys' authority to make decisions for Annie and providing appropriate medical care for Annie, although delicate and difficult to accomplish, is vital to minimizing the negative effects of ethical dilemmas.

RESOLVING ETHICAL ISSUES

It is perhaps too optimistic to believe that the health care team and the Bradleys can easily resolve the ethical issues attendant in Annie's case. Instead, there may be options to reduce the tension caused by these ethical concerns.

Of course, every case of a premature neonate is different and options may be successful in one case, but fail in a subsequent case.

Encouraging a second opinion is one possible avenue to achieving a balance that respects the Bradley's ability to make decisions for Annie while avoiding unnecessary suffering by Annie. No doubt, during the tenuous ordeal of Andy and Annie, the health care team and the Bradleys developed an emotionally tense relationship. An outside expert may provide the Bradley's an unbiased opinion of Annie's prognosis, which may aid the Bradleys to comprehend their daughter's grave condition. However, if the Bradleys are steadfast in their determination to do everything possible, while hoping for a miracle and vowing not to lose another child, a second opinion may not realistically ease the tension between the Bradleys and the health care team.

Similarly, if the health care team believes that it is providing medically inappropriate care that is causing unnecessary suffering, the physicians could recommend transferring the care of Annie to other physicians or another hospital. Before transferring though, the parties must find physicians or a hospital willing to accept Annie and care for her. During the interim, the health care team must continue to care for Annie, or they risk claims of abandoning Annie. Transferring care may be an ultimate goal, however it does little to solve the current ethical dilemmas.

In Annie's case, legal recourse is not a beneficial avenue to resolving the ethical dilemmas. It is quite unlikely that the hospital would pursue legal action to either remove the Bradleys as Annie's decision makers or to request authorization from a court to withdraw care. Taking legal action in this case is an extremely drastic step and will undoubtedly cause increased tension between the Bradleys, the hospital, and the physicians. Legal action would likely only be necessary when it is apparent that the Bradleys are intending to cause suffering or harm to Annie by demanding aggressive treatment. Rather, the Bradleys' emotional state, coupled with their hope for a miracle, is driving their desire to continue aggressive treatment. Nothing indicates that the Bradleys are intentionally causing Annie to suffer, which obviates legal intervention.

Ultimately, the most effective method to handle the ethical dilemmas in Annie's ordeal is to have open and frank discussions about Annie's prognosis. Certainly, having seen many similar cases in the past, the health care team understands the low likelihood of survival and the pain associated with aggressive treatment. But, the health care team must appreciate the Bradleys' desire not to give up on their child. Ideally, the health care team should discuss with the Bradleys, perhaps even before the children are even born, the anticipated medical treatments and consequences of initiating aggressive treatment. This enables the Bradleys to anticipate the complications that may arise, evaluate the options, understand the consequences of their decisions, and formulate a goal for treatment. Having honest communication with the Bradleys about the struggles Annie will face and the consequences of aggressive care may help the parents make informed decisions in Annie's best interest. Likewise, achieving a common goal for Annie's treatment at the outset, though recognizing that the goal may change based on the circumstances may reduce the likelihood of these ethical issues from detrimentally interfering with Annie's care.

CONCLUSION

Clearly there is no single right or wrong way to handle Annie's ordeal. Transferring care and legal intervention are both options, but in this delicate and emotionally charged atmosphere, these are options of last resort that do little to resolve the current issues. A second opinion may be sought to confirm the low likelihood of Annie's survival, but effective and constant communication between the Bradleys and the health care team is the ideal method to diffuse the negative impact of ethical issues. It is unrealistic to believe that ethical issues can always be avoided, but with effective communication, the potential for ethical showdowns between parents and the health care team can be drastically reduced.

REFERENCE

1. O'Connor CM, Lorah KN. Dilemmas At The Beginning Of Life: Biomedical Ethics in the Newborn. J Lanc Gen Hosp 2008;3:102-104.

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