Bioethics Case Analysis

This is the case of a 23 wk 530 g AAM who had been born in house and presented to the Neonatal Intensive Care Unit in severe respiratory distress. He was intubated and had lines placed in the umbilical artery and vein. He required pressor support, antibiotics were started and life support was maintained by the ventilator. Day by day, he seemed to be making no real improvement. He was not expected to survive day of life 1, but he continued to live; some days slightly improving but then getting worse the next. He was still living at day of life 7 but his various organs were failing. He had stopped producing urine, he was on three pressors: dobutamine, dopamine and epinephrine but was still not maintaining an adequate blood pressure. The physicians had been in communication with the mom throughout the week about the situation, but she wanted “everything to be done” so we continued to add various medications and increase the settings on the ventilator. He also had suffered a grade III interventricular bleed indicated on his head ultrasound. He continued to decline until dying on day of life 8. The mother throughout his life refused any withdrawal of life-sustaining support.

The only people involved in this case were the nurse practitioner, nurses, the neonatologist, the mom and the grandmother. She was a young, single, competent person who seemed to have good support from her own mother. The grandmother always came with the young mother whenever she came to visit.

The ethical issues presented in this case are: Should the quality of life be an issue? Are some babies too sick or premature for neonatal intensive care? Who decides whether or not an infant receives care? Is withdrawing support ethically acceptable in the case of severe IVH?

Who decides whether or not an infant receives care is decided based on the age of the infant. At 25 weeks or greater, resuscitation is given despite the feelings of the
parents. Infants 24 weeks and less, the parents make the decision. The American Academy of Pediatrics Committee on Bioethics supports the involvement of parents on decision making and believes that parents and physicians should make reasoned decisions together about critically ill infants using informed parental consent as long as the parents can accept the responsibility of nurturing the infant and providing reasonable care. In rare cases when parents want to forego life sustaining medical treatment, and the physicians disagree and can’t resolve their differences; child protective services, subspecialists or an ethics committee may have to be consulted.¹

Are some babies too sick or premature for neonatal intensive care? Is there a limit on providing life sustaining treatment for the extremely premature? There were some major concerns raised by several physicians over the Born-Alive Infants Protection Act of 2002 and its implications for neonatal practice. Born-Alive Infants Protection Act has been interpreted by the Secretary of the US Department of Health and Human Services to mean that the department “will investigate all circumstances where individuals and entities are reported to be withholding medical care from an infant born alive in potential violation of federal statutes for which we are responsible.” Dr. Sayeed in Pediatrics, says that the law could have a potentially harmful effect: “The current administration's resurrection of recently quiescent oversight of the treatment of imperiled newborns agitates the legal fault line that physicians walk along when caring for these infants.” Failure to resuscitate a 21 week gestational age infant or withdrawing treatment from infants “at the soft margins of viability” at 22-23 weeks could be taken as a violation of the law. Of these patients a small percent survive and the majority of them with significant neurologic impairments.² About 20% survive at 23 weeks, 40% at 24 weeks and 60-70% at 25 weeks gestational age. So far, birth weight has been the most significant factor in whether or not an infant survives. The past decade has seen the most improvement in the survival rate of infants with the birth weights between 470-700g now at 33%.³ Most physicians will resuscitate a 23 week gestational age infant but there is controversy on whether or not to resuscitate infants at 22 weeks or younger.

Is quality of life even as issue? While most physicians believe that quality of life should be a factor in deciding the best treatment or whether or not to withdraw
treatment, the definition is somewhat vague. In the social sciences, the definition is the "ability to engage in life tasks and derive satisfaction from doing so. To have life tasks, to gain satisfaction from engaging in them, and to have values on the basis of which one can judge whether the extent of one's satisfaction is sufficient and therefore makes one's life worth living." It would be hard to use this definition with a neonate. The American Academy of Pediatrics does not exactly define what constitutes a “diminished quality of life” so severe that it would be better for the infant to be allowed to die. Richard McCormick, a prominent Catholic bioethicist, felt that “withholding or withdrawing treatment from a child was ethically justified if the child lacked the ability for interaction or human relationship.” Similarly, Nancy Rhoden has supported a provision to the Child Abuse Amendments of 1984 to allow withholding treatment if a child, "lacks potential for human interaction as a result of profound mental retardation." Quality of life is a factor, and a relational ability standard for withholding or withdrawing life support is supported by many bioethicists.

Is withdrawing support even ethically acceptable in the case of severe intraventricular hemorrhage (IVH)? Grade I IVH describes an infant with a subependymal hemorrhage, grade II an infant with IVH without ventricular dilation, grade III an infant with IVH and ventricular dilation, and grade IV an infant with IVH and parenchymal hemorrhage. In some of the early reports, mortality rate from severe IVH was as high as 60% and major long-term disabilities were found in up to 90% of survivors. Based on this data, many neonatologists decided to withdraw care especially when there was continued deterioration of the infant. It is a harder decision when the infant has a grade IV bleed and is hemodynamically stable. The practice of withdrawal of life support from premature infants with severe IVH based on quality of life is potentially supported by the AAP Policy Statement on Noninitiation or Withdrawal of Intensive Care for High-Risk Newborns. “According to this statement a decision to withdraw care may be justified in cases where the, ‘prognosis is uncertain but likely to be very poor and survival may be associated with a diminished quality of life.’”

Recent data may cause the neonatal world to reevaluate the withdrawing care based on quality of life. “In 2007, Bassan and colleagues, reported on the neuromotor, visual,
developmental, and adaptive outcomes of 30 premature infants with grade IV IVH at 30 months. In this study the authors’ reported that despite two thirds of infants developing significant cognitive and/or motor abnormalities the vast majority of infants had relatively good adaptive outcomes, including 80% with adaptive social scores and 87% with adaptive communication scores within 2 SD of normal.\textsuperscript{8} The mortality rate of an infant with a grade IV IVH is between 30-40%. This is not good but does it justify withdrawing support especially in the light of the recent data? If the child has a significant bleed and is continuing to deteriorate despite intervention (like the infant in the case), the withdrawal of care may be appropriate as we may be prolonging the dying process instead of sustaining life. The case of the child that is doing relatively well and has a significant bleed would be harder to justify ethically in light of recent data.

The aim of all treatment is to act in the babies’ best interest. Sometimes it is unclear what course of action is in the best interest of the baby. This is when open communication between the physician and the parents is vital to help make these agonizing decisions. In the case, the physicians did the right thing by abiding by the mother’s choices although withdrawing care would have been ethically appropriate as well due to his failing condition. Prolonging death was the most correct assessment of the situation. As John Wyatt says, “It is not our place to make value of life decisions, deciding which life is worthwhile and which life is futile. But it is our place to make treatment decisions, deciding which treatment is worthwhile and which is futile.”\textsuperscript{9}
References


4. “Neonatal Ethics at the Limits of Viability.”


6. Ibid.

7. Ibid.

8. Ibid.