



DILEMMAS AT THE BEGINNING OF LIFE:

Biomedical Ethics in the Newborn

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INTRODUCTION

Perhaps the most onerous medical decisions, because of their gravity, are those that involve the medical care and treatment of either premature neonates, or neonates with life-threatening or lethal syndromes or anomalies. Because such decisions are fraught with ethical and legal dilemmas, effective communication between the health care team and the newborn's parents is essential.

Ethical issues in the newborn have been described since Biblical times. King Solomon's legendary wisdom was demonstrated by his resolution of the ethical dilemma presented by two women who both claimed to be the mother of the same child.¹ Today, obstetrical and neonatal providers are called upon to discern truth from near-truth and to act in the best interest of the newborn, while also respecting the parents' right to make medical decisions for their child. Upsetting this delicate balance can lead to explosive showdowns between parents, health care teams, and the state.

In this article we will introduce the ethical and legal dilemmas inherent in neonatal care, with a focus on end-of-life care. In two subsequent articles in this three-part series, we will use a case study approach for more in-depth discussions that demonstrate how ethical and legal issues arise when treatment decisions must be made for newborns. More importantly, we will discuss how health care providers can avoid ethical and legal confrontations.

ETHICAL DILEMMAS

The cornerstone of bio-medical ethics is defined by the principles of autonomy, beneficence, non-maleficence, and justice. The three most common neonatal situations which require application of these ethical principles are: 1) fetuses at the lower gestational age limit of viability;

2) neonates with life threatening/life limiting congenital anomalies and syndromes; and 3) the deteriorating, acutely ill newborn in intensive care with a grave prognosis.

Many ethicists and physician organizations have weighed in on appropriate application of the four ethical principles in neonates. For example, in regard to resuscitation of neonates, the American Academy of Pediatrics and the American Heart Association Neonatal Resuscitation handbook² states:

The ethical principles of neonatal resuscitation are no different from those followed in resuscitating an older child or adult. Common ethical principles that apply to all medical care include respecting an individual's rights of freedom and liberty to make changes that affect his or her life (autonomy), acting so as to benefit others (beneficence), avoiding harming people unnecessarily (nonmaleficence), and treating people truthfully and fairly (justice). Exceptions to this rule include life-threatening medical emergencies and when patients are not competent to make their own decisions. Neonatal resuscitation is a medical treatment often complicated by both of these exceptions.

Although, the four ethical principles must be considered when making decisions regarding treatment for newborns, the principle of autonomy is the usual source of contention between a health care provider and the newborn's parents.

Autonomy recognizes each individual's right to decide what medical treatment is appropriate for him or herself. This means that an adult of sound mind can refuse medical treatment, even if that refusal will likely result in death. But when faced with end-of-life decisions in

newborns, who makes those medical decisions on behalf of the newborn? Across the country, it is well settled that the parents are the decision-makers for the newborn. Yet, in extreme cases, states have the ability to usurp parental authority. Less settled, however, is the degree to which parents' moral and religious beliefs should influence treatment decisions. Who determines what to do when the parents' moral and religious beliefs favor treatment decisions to the detriment of the newborn?

Application of ethical principles in neonatal care is further complicated by the fact that the health care team seldom has accurate, complete, and reliable information. For example, despite the great strides that have been made in imaging technologies, limitations still exist in identifying potential syndromes or anomalies prior to delivery. Ante-partum estimates of fetal weight by ultrasound are only accurate within $\pm 15\text{-}20\%$. Obstetrical dating is only accurate to $\pm 1\text{-}2$ weeks, unless conception occurred by in vitro fertilization. These figures may not be significant in a full-term pregnancy, but when considering the lower limits of viability, two weeks and a 20% weight disparity can be the difference between a 5% survival rate and a 43% survival rate. When discussing relevant information with parents, it is imperative that the physician present this degree of uncertainty.

LEGAL DILEMMAS

Two principal legal challenges face health care providers who treat newborns at the limits of viability, or those suffering from life-threatening or lethal syndromes or anomalies. First, the health care team must be cognizant of the federal "Baby Doe" regulations, which detail when it is appropriate to remove life-sustaining treatment. Second, the health care team should be aware of the availability of legal options should it become necessary for them to take action to protect the newborn.

After a highly publicized newborn case in Bloomington, IN in the early 1980s, the federal government pronounced that hospitals unlawfully discriminate if treatment is withheld from newborns inflicted with a disability. The case centered on the parents' refusal to consent to a surgical procedure in a newborn suffering from Down's syndrome, ultimately leading to the death of the newborn. Regulations issued by the Department of Health and Human Services (HHS) stated that a hospital discriminates against a newborn if the hospital refuses to provide life-sustaining treatment to a child

with a disability. The regulations also imposed numerous notification and enforcement requirements on hospitals. Ultimately, the United States Supreme Court declared the "Baby Doe" regulations an unconstitutional exercise of power by a federal agency.³

HHS revised the regulations to recognize that withholding treatment in a disabled newborn with a life-threatening condition is akin to medical neglect, unless treatment of the newborn would merely prolong the process of dying, be futile, or be inhumane.⁴ The second set of "Baby Doe" regulations have not received the scrutiny the initial regulations received, but the practicality and benefit of the "Baby Doe" regulations remain contentious among ethicists and neonatal providers.

A health care team treating a newborn that has life-threatening ailments or is at the limits of viability might disagree with the medical decisions made by the parents, but might not know which legal principles apply in their patient's particular situation. In Pennsylvania, hospitals have two options. The first is to seek a court-appointed guardian to replace the parents as decision-makers, but this route is cumbersome and impractical when immediate treatment decisions must be made. A more practical option is for the hospital to take temporary custody of the newborn, which allows the hospital, in conjunction with the county child services office, to make treatment decisions for the newborn. In addition, the local county child services office will then pursue permanent custody through the court system.

Although the hospital and health care team have legal options at their disposal if they feel the parents are not making decisions in the best interest of the newborn, it is best to avoid these legal maneuvers, and to view them as a final option only after the health care team and the parents have explored all other options.

AVOIDING LEGAL CONFLICT

As with all medical decisions that are flavored with ethical or legal considerations, avoiding legal conflicts in the treatment of newborns is ideal. To accomplish this goal, it is imperative that the health care team and the parents communicate effectively.

The framework for effective communication is identical whether identification of a life-threatening or lethal syndrome or anomaly occurs prior to or after

delivery. First, it is incumbent upon the perinatologist or neonatologist to ensure that the parents have a comprehensive understanding of the existing condition. If parents cannot grasp the implications of the existing condition, they may not process crucial information. After the existing condition is identified and the parents understand it, the bulk of the discussions will focus on the information that is known (and unknown), and its implications for the neonate (including morbidity and mortality rates or ranges).

The health care provider should also discuss the availability of perinatal palliative care services, if appropriate. These discussions will enable the health care team and the parents to develop guidelines for intervention and treatment during the peripartum period. Parents must understand that the agreed-upon guidelines are subject to modification as more information becomes available. Since the intervention and treatment guidelines are fluid, the health care team and the parents must constantly communicate so that any disagreements between them can be identified and dealt with before treatment decisions are necessary. This plan will hopefully avoid the

ethical and legal showdowns that result when immediate treatment decisions are needed, and disagreements occur when emotions are at their peak.

CONCLUSIONS

End-of-life decisions at the beginning of life are taxing on both the health care team and the parents. Health care providers must respect the parents' right to make medical decisions for their own children, but they should also be aware of their legal options when they believe - based on the medical information available - that the parents are not making medical decisions in the best interests of the newborn.

Ultimately, disputes surrounding the treatment of newborns occur in two instances. The first is when the health care team believes further treatment is inappropriate and unethical, yet the parents demand continued treatment. The second is when the health care team believes continued treatment is appropriate, yet the parents demand an end to all treatment. These disputes can and should be avoided by effective communication between the health care team and the parents.

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