



III. DILEMMAS AT THE BEGINNING OF LIFE: BIOMEDICAL ETHICS IN THE NEWBORN

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INTRODUCTION

This is the third and final article in a series that focuses on ethical and legal issues in premature neonates. We present another hypothetical case in which the parents refuse medical treatment for their extremely premature newborn that likely would save its life. Their decision goes against the medical advice of the health care team, and this article highlights the state's justification for imposing limitations on the authority of parents to make decisions for their children.

CASE PRESENTATION

Jim and Sandy Brown had a difficult year; Jim was laid off from his printing job and Sandy struggled to keep the house in order with two preschool boys. The news of her pregnancy was unexpected and added stress to their lives. When Sandy developed vaginal bleeding at 25 weeks gestation (fifteen weeks before her due date) they were not prepared for the birth that was now apparently imminent. Sandy was admitted to the hospital and stabilized. She received tocolytics and antenatal steroids. The Browns met with Dr. Callahan, a neonatologist, who discussed the most common diagnoses, treatments, complications, and outcome for infants at 25 week gestation. It was a lot for them to digest, but the numbers the Browns remembered were a 25% chance of death for their baby, and if he did survive, a 50% chance of moderate to severe neurodevelopmental impairment. What was actually said was that at 25 weeks gestation and 750 grams (about 1 pound 11 ounces) there was a 79% chance of survival and of those survivors, about 53% were "intact" – without moderate to severe impairment.

After a brief and strained discussion with his wife, Jim asked to talk to the neonatologist again. He told Dr. Callahan that if the child required extensive medical treatment after birth, they had decided against any "heroic" measures because they did not want their

child to go through life "with problems". Because of the likelihood of the child surviving, albeit with medical intervention, Dr. Callahan stressed that the probable medical treatment necessary to save the newborn's life was the prevailing standard of care: not inherently risky, relatively straightforward, and with a high success rate. However, it became apparent that the Browns did not want what is considered standard of care treatment for their baby because of the potential burden of raising a child with neurodevelopmental impairment.

Such a scenario initiates a medical and ethical struggle for the health care team. How do they balance respect for the wishes of the parents with defending the rights of a newborn whose likelihood of survival after standard treatment is quite high? What options are available to the health care team in order to resolve this dilemma?

IMPACT ON PARENTAL AUTHORITY

One principle of medical ethics that is perhaps the most fundamental, is patient autonomy. This principle recognizes a patient's ethical and constitutional right to make medical decisions about themselves, even if the decisions are "bad" ones. In the present case, the ethical dilemma would be less onerous if the patient were an adult of sound mind who had been apprised of the consequences of making a "bad" decision, yet had chosen to make such a decision. But the principle of autonomy is complicated when the health care team is faced with a substitute decision maker, in this case a parent acting on behalf of an infant. Does a substitute decision maker have the same degree of autonomy as a competent patient?

In the scenario presented above, no one doubts the Browns' right to make decisions for their own child. However, questions arise about the limits of such rights. Are the parents' rights practically infinite (as is the case for an adult of sound mind), or are there boundaries to

the parents' rights? If there are boundaries, what are they and who imposes them? Can parents legally make "bad" medical decisions for their children?

JUSTIFICATION FOR LIMITATIONS ON PARENTAL AUTHORITY

Legally, it is well settled that parents do not have absolute rights to make decisions for their children, whether about medical care, education, or employment. The state, acting as *parens patriae*, can and does require school attendance, and places limitations on a minor's employment hours or working conditions, regardless of what the child's parents decide. Some of those limitations have broad implications that go beyond the scope of this article; we will discuss only how the law restricts a parent's right to make medical decisions for a child. The state certainly recognizes that a child's parents are the decision makers for their child, but in limited circumstances the state's interest in protecting the child outweighs the parents' right to make decisions. When the child's welfare is at issue, the state's authority to restrict parental authority is heightened.

Relating to medical decisions, a parent has the authority to make most decisions for their child, but a parent does not have the right to make decisions that subject the child to ill-health or death. For example, parents can decide whether their child will receive the influenza vaccine or whether the child will participate in a research trial, but a parent cannot refuse a blood transfusion that would save the life of the child, nor refuse nutrition in a malnourished child, even for religious reasons (see below).

In reviewing legal opinions and statements, and the views of bioethicists, there appears to be an imaginary line between decisions that immediately imperil a child's health, and those that do not. Hence, the parent's right to make decisions for a child whose life is in jeopardy may be limited by the state's heightened interest in protecting the child. On the other hand, when the child's life is not in jeopardy, the state is less likely to intrude upon the parent's right to make decisions.

Another influence on this dichotomy is the likelihood of success of medical intervention when the child's life is in immediate peril. The greater the likelihood that treatment will be successful, the greater the state's authority to restrict the parent's right to make decisions. For example, if a child has a terminal illness for which

there is no known cure, it is unlikely that the state has the authority to require parents to enroll the child in a Phase I drug research trial. The child's life is clearly in peril, but the proposed research trial has high-risk and unknown benefit; no one would seriously question the parents' decision to refuse to enroll their child, or argue that this is a "bad" medical decision. The state's interest in protecting the child is not furthered by compulsory enrollment in a research trial. However, if a child's life is in jeopardy, and the threat can be lifted by a relatively simple medical procedure, the parents are unlikely to legally sustain a refusal of medical treatment. The state's intervention is justified to protect the child.

In the scenario presented at the beginning of this article, the child may suffer from a potentially debilitating, life-threatening disease, yet standard medical treatment can save the child. Regardless of the parents' reason for refusing treatment, be it religious, philosophical, or financial, the state's interest in protecting the child trumps the authority of the parents to refuse treatment. Here, a child is suffering from a disease that has a straightforward and accepted treatment with a relatively high success rate and generally acceptable long-term negative effects. (It is relevant that regardless of the outcome, the state would not directly support or assume responsibility for the disabled child. However, the child would probably be eligible for a state Medicaid plan, disability payments, etc., so that the state would, in all likelihood, ultimately be supporting the child.) In a decision between a treatment that will most likely be successful, and imminent death if the treatment is refused, the state requires the parents to consent to the procedure. The state is justified in interfering because a child, unable to speak for itself, should not suffer the consequences of its parents' "bad" decision.

LEGAL RECOURSE FOR HEALTH CARE TEAM

Since the state may usurp the decision making authority of parents in certain circumstances, numerous state laws have been passed to protect children from their parents' "bad" decisions. Pennsylvania authorizes a hospital to take temporary custody of a child if doing so is necessary to protect the child.¹ The hospital taking temporary custody must notify the child's parents that it is doing so. Within 24 hours of taking custody, the local child protective service agency must be notified, and becomes responsible for initiating court proceedings to permit continued custody of the child.

A hospital may take temporary custody of a child if it suspects the child is being abused, or if it believes the parents are making decisions that place the child's health or well-being in substantial jeopardy. After the child is placed under temporary custody, a court will likely appoint a guardian to oversee the child's care. For example, a child who requires a blood transfusion that parents refuse on religious grounds, will likely have a guardian appointed to consent to the blood transfusion after the hospital and local child protective service agency have taken custody of the child.

In a situation where time is of the essence to protect the health of a child, a hospital may seek the appointment of an emergency guardian. In such cases the hospital petitions the court directly to immediately issue a court order appointing a guardian of the child. The guardian is required, by law, to act in the best interest of the child.

In our scenario, it is most likely that the hospital would take temporary custody of the child in order to initiate treatment to save the newborn. In deciding whether a guardian

should be appointed, thus removing the parents' right to make any decision for the newborn, the court would focus on the diagnosis, the prognosis, the risks of treatment, and the likelihood of success. If the court determines that the parents are not making decisions in the best interest of the newborn, the court likely would appoint a guardian.

CONCLUSION

Recently, there have been a handful of cases in the national headlines that related to the preventable death of a child as a result of the parents' refusal to seek medical care. In a few cases, criminal charges, even manslaughter, have been filed against the parents who refused to seek medical care when their child was gravely ill. It is these types of cases in which the state's legitimate interest in protecting the welfare of a child trumps the ability of the parents to make decisions for their children. Although many states have implemented laws allowing for the removal of parental decision making authority, these laws are intended to be used sparingly, as a last option, and only in extreme cases where the parent is refusing treatment that will likely save the life of the child.

REFERENCE

1. 23 Pa.C.S.A. 6315.

Neither Dr. Lorah nor any member of his immediate family have any relevant relationships to disclose with any corporate organizations associated with the manufacture, license, sale, distribution or promotion of a drug or device.

Neither Mr. O'Connor nor any member of his immediate family have any relevant relationships to disclose with any corporate organizations associated with the manufacture, license, sale, distribution or promotion of a drug or device.

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