

Two Infants, Same Prognosis, Different Parental Preferences

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abstract

A central principle of justice is that similar cases should be decided in similar ways. In pediatrics, however, there are cases in which 2 infants have similar diagnoses and prognoses, but their parents request different treatments. In this Ethics Rounds, we present such a situation that occurred in a single NICU. Three physician-ethicists analyze the issues.

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One of the toughest situations that arises in pediatrics is when 2 infants in the hospital at the same time have the same disease, the same prognosis, and require the same treatment, but, in 1 case, the parents want everything done, and, in the other case, the parents choose end-of-life comfort measures only. We know that different parental choices are permissible, when the indications for treatment are ambiguous and the prognosis uncertain. Yet it feels odd when the patients are in the hospital at the same time, perhaps side by side in the same unit, and caregivers work to keep 1 patient alive while providing palliative end-of-life care for the other. Such cases force us to look at the rationale for life-prolonging treatment or for palliative care. We present such a situation and ask for comments from Armand Antommara, MD, PhD, a pediatric hospitalist and Director of the Ethics Center at Cincinnati Children's Hospital Medical Center; Ryan Antiel MD, MA, a resident in surgery at the Mayo Clinic; and Chris Collura, MD, a neonatologist and bioethicist who is completing training in pediatric palliative medicine in the Harvard Palliative Care Fellowship.

THE CASES

A 45-year-old G₁₂P₉ Amish mother delivered a premature infant at

33 weeks. After difficulty feeding, doctors diagnosed proximal esophageal atresia with tracheoesophageal fistula (TEF). The infant underwent TEF ligation with planned delayed anastomosis of the esophagus given the degree of gap length. Postoperatively, several attempts at extubation failed. Bronchoscopy revealed severe tracheomalacia at the level of the ligated TEF pouch.

The medical team recommended tracheostomy with chronic mechanical ventilation for a period of months to years until the infant's growth could optimize surgical repair. Head ultrasounds were normal.

The family had many concerns. They had no electricity at home and realized that the infant would have to be placed in long-term care as long as mechanical ventilation was necessary. In addition, such an intervention would incur significant costs. Consistent with most Amish, the infant's family refused state-sponsored medical assistance including Medicaid.

The family refused tracheostomy and requested compassionate extubation and comfort measures for their child.

A second patient cared for concurrently in the same level III NICU had also been diagnosed with TEF. This neonate had been born by caesarian delivery as a premature twin at 31 weeks'

gestation to a 29-year-old G₂P₁ mother. Shortly after birth, a diagnosis of esophageal atresia with TEF was made.

Unlike the first patient, primary anastomosis of the esophagus was performed. The postoperative course was complicated by cardiac tamponade secondary to pericardial effusion of parenteral nutrition from a central venous line. The infant recovered after emergent pericardiocentesis and prolonged cardiorespiratory resuscitation.

The remaining hospital course was marked by multiple failed trials of extubation due to persistent airway obstruction. Severe distal tracheomalacia was diagnosed. Despite an unclear neurodevelopmental prognosis because of prolonged cardiopulmonary resuscitation, the medical team recommended tracheostomy with chronic mechanical ventilation for a period of months to years. The parents accepted these recommendations.

The NICU staff was troubled by these decisions. Some felt that in case 1, treatment was more clearly in the infant's best interests because the long-term prognosis was better. The staff struggled with the ethics of whether both decisions were permissible. Given the family's beliefs that chronic technology-dependent intervention not consistent with their value-driven desires for their child, should the NICU medical team accept the parents' request to withdraw ventilatory support in this Amish infant? Should they recommend treatment in the other case?

ARMAND AN TOMM ARIA COMMENTS

The initial component of any case analysis is clarifying the situation. In the first case, it would be important to clarify the implications of the parents' religious beliefs for the patient's care. The Amish are 1 of a group of denominations that

developed out of the Protestant Reformation collectively known as the Anabaptists (rebaptizers) because of their insistence on adult baptism. Contemporary Amish have different church districts that may interpret religious regulations differently.¹ There may, therefore, be a wider range of options acceptable to the parents than the case description suggests.

Although the Amish use alternative and traditional medicine, they also use contemporary, allopathic medicine.^{1,2} They are not opposed to technology per se. Instead, they adopt it selectively with the goal of building community and preserving social capital. As an example, the Amish forbid using 110-V current from public utility lines, but they do not prohibit all uses of electricity. Generators are permitted to power welders and carpentry tools and to recharge batteries. Inverters may be used to convert 12-V current from batteries into 110-V current. In some cases, exceptions have also been made for medical equipment. These distinctions are important to determine whether, in this case, it could be technically feasible and ethically acceptable to care for the patient at home.

The Amish value self-reliance and community autonomy. They believe it is the church's responsibility to care for its members. They therefore refuse to participate in Medicaid, Medicare, or commercial insurance programs. It would be important to clarify the degree to which the family's objection to long-term care is based on familial or community obligations to care for the infant or on financial concerns. Additional financial resources may be available to the family within their own district or from adjoining districts. Some districts participate in an informal community-based hospital insurance called Church Aid. The amount of resources required for home mechanical ventilation might,

however, be considered poor stewardship.³

For the sake of argument, let us stipulate that either the treatment is ethically unacceptable to the parents or they are unable to pay for it. One could analyze the case using either a principle- or case-based approach. Preferring a case-based approach, I would frame the issue as whether the refusal to provide mechanical ventilation constitutes medical neglect. Parents have broad discretion in the care of their children, but the state is justified in intervening in cases of abuse or neglect. In addition to failing to provide adequate food or shelter, the failure to provide adequate medical care can constitute neglect. In evaluating suspected cases of neglect, the primary focus should be on the effects on the child rather than on the parent's reasons. Even loving or well-intentioned parents can seriously harm their children. Religious justifications for refusing medical treatment therefore do not have special standing.⁴

The clearest cases of medical neglect involve the failure to provide discrete, lifesaving interventions that are highly efficacious and have limited side effects. The classic example is administering court-ordered blood transfusions to children whose parents are Jehovah's Witnesses to treat acute blood loss. Although blood transfusions have risks, major risks are infrequent. The risk of contracting hepatitis B, for example, is <1 in 800 000 U. Judicial decisions are less consistent when the condition is not immediately life threatening or the treatment is prolonged, has limited efficacy, or has significant side effects. Examples include chemotherapy and organ transplantation. For example, even though liver transplantation is an effective treatment of life-threatening fulminant hepatic failure, it requires lifelong immunosuppression that entails significant risks including infection.

At the other end of the spectrum, courts have usually declined to intervene in cases where the disease was disfiguring but not life threatening. Gathering accurate information regarding the conditions under which the courts have intervened is difficult because there is no systematic recording of trial court decisions.

Prolonged mechanical ventilation is likely to fall within the gray zone. It can be lifesaving but is an ongoing intervention that entails significant risks. These risks include tracheal injury, respiratory infection, and impaired communication skills and swallowing.⁵

A traditional principle-based approach, focusing on the child's best interests, also produces an indeterminate result. There is controversy about the effects of mechanical ventilation on the individual's quality of life, the degree of burden on the caregivers, and how these factors should be weighed. Objectively, children who require prolonged mechanical ventilation tend to report decreased health-related quality of life compared with other children with chronic illness. Subjectively, they report their quality of life is acceptable.⁶ Caring for a technology-dependent child can be enriching, but it requires significant effort from the caregivers. These burdens may, however, be decreased by improved societal support.⁷

Even if this level of care giving is not morally obligatory, relinquishing custody would be an alternative to withdrawing life-sustaining treatment. A child could be cared for in an intermediate care facility or taken into state custody. Although children who lack a bonded caregiver have poorer developmental outcomes, it is not clear that their outcomes are so poor that they would be better off dead. Preferable alternatives might be a medical foster home, if the child may eventually be weaned off the ventilator, or adoption.

The situation in the first case strikes me as exceptionally sad. Interpreting the case charitably, the patient's parents love their child and are trying to do what they believe is best for him or her. Removing the child from their custody arguably increases the risk for a poor outcome. Although others may reasonably disagree, I am inclined to argue that the child's interests should be primary and that mechanical ventilation would be an effective, time-limited intervention with a favorable benefit-to-risk ratio. I believe that state intervention would be justified if an appropriate placement were highly likely.

With respect to the second case, it appears that the medical team also recommended a tracheostomy and continued mechanical ventilation. The parent's preferences are not clear. If the parents were to refuse, one would need to consider whether the patient's potential neurologic impairment alters the analysis of his or her interests. Most individuals with neurologic impairment are capable of having interests, including an interest in life-sustaining treatment. They should be protected against discrimination. Individuals with profound impairments may not, however, be capable of having interests, or their interests may be significantly reduced. More information would need to be provided about the patient's potential neurologic outcome to fully analyze the second case.

The key question, about which individuals may reasonably disagree, is whether, in these 2 similar situations, withdrawing mechanical ventilation constitutes medical neglect. If it does, both infants should receive mechanical ventilation, either as a result of parental consent or state intervention. If it does not, parents may choose to continue or withdraw mechanical ventilation based on their values and beliefs. In the latter case, different outcomes may be ethically appropriate.

Understanding why different outcomes may be ethically acceptable may help reduce the staff's moral distress.

CHRISTOPHER COLLURA COMMENTS

These families present what are most likely very different cultural, religious, and socioeconomic perspectives that inform disparate requests for their seriously ill infants. The Amish family relies on a value framework that heavily weighs the burden of the intervention as well as the financial resources of the family and community to contribute to their request to withdraw ventilator support. The other family acknowledges neuroprognostic uncertainty and elects to pursue tracheostomy and chronic mechanical ventilation. Analysis of these 2 divergent paths should prompt a systematic method in determining the ethical construct of each process.

The American Academy of Pediatrics (AAP) has advocated for a patient-centered approach when considering intensive medical interventions for newborns. Any proposed treatment must be assessed as to whether it is consistent with the child's best interests.⁸ In these cases, the medical teams must first consider the benefits and burdens of tracheostomy and chronic mechanical ventilation for these 2 children. The providers must weigh the likelihood of survival and cognitive and psychomotor prognosis against the invasive and long-term physical burden of the treatment.

Tracheostomy for indications of airway obstruction has demonstrated favorable long-term survival and successful decannulation in the majority of patients.^{9,10}

Tracheostomy may facilitate conscious engagement in emotional, physical, and intellectual activity for the 2 neonates described in the cases. Burden assessments often require value-laden judgments about an intervention's impact on quality of

life. Limited data suggest that children who undergo tracheostomy face significant risk for serious postoperative complications including critical cannula obstruction, displacement, tracheal necrosis, and death. Less serious complications are much more common and include bleeding, granuloma, and skin wounds.² The overwhelming majority of children with tracheostomy will experience lung infections.³ Many infants who receive tracheostomies have developmental delay and cognitive impairment,^{11,12,13} but it is difficult to disentangle the effect of the tracheostomy from the effect of their underlying diseases. Patients with tracheostomies and chronic ventilation require access to tertiary subspecialists, intensive home provider education, and home health care equipment, supplies, and staff.

Tracheostomy and chronic mechanical ventilation may optimize both infants' chances for long-term and developmentally engaged survival. Although invasive tracheostomy and chronic ventilation is burdensome and presents severe risks, the physical impact of the treatment does not clearly outweigh its benefits. The medical teams can confidently offer this intervention based on the best interests assessment. The question becomes whether this intervention is morally and legally obligatory.

Just as the AAP advocates for a patient-centered approach, it also maintains the vital role of parents in decision-making. Parents' cultural, religious, educational, social, and ethnic backgrounds often present complex values and decision-making perspectives that may diverge starkly from that of physicians. These views should be respected as parents and medical teams make rational decisions together concerning the care of the child.¹⁴

For the Amish patient, the parents request to withhold tracheostomy and withdraw the ventilator. The

decision considers the financial burden of long-term medical treatment on their family and community. The transition to home would likely have been precluded by the community's restricted access to electricity and the rural geographic limitations to home care providers. Options for long-term care could have included a skilled nursing facility or medical foster home. The financial considerations of the Amish family described in the case are intrinsic to the social fabric of the Amish community. Although resource allocation is rooted within the cultural construct of the Amish, there is no societal precedent that allows it to be the sole driver determining withdrawal of life-sustaining medical treatment.

Presuming the best intentions, the parents' decision was additionally likely rooted in their own benefit-burden assessment for their infant. Given their request to withdraw the ventilator, it may be reasonable to conclude that the parents gave less weight to their child's survival than to the degree of physical impact invasive and long-term medical technology dependence would have on the infant's quality of life.

The medical decision-making regarding tracheostomy rarely presents itself as a clear benefit with minimal burden. Providers should override family wishes only when there is definitive evidence that the family's surrogate decision-making is contradictory to the infant's best interest.¹⁵ Although the best interest standard lends itself to offering the intervention, burdens of the proposed treatment are not minimal. Because of this, it is less clear whether this same assessment should morally compel state custody, invasive surgery, and long-term technology dependence against parental values. Medical decision-making for the Amish infant falls into a gray zone.

The ethical framework for each case defaults to prioritize well-informed

parental authority on behalf of the child. All efforts should be made to medically educate the family, explore options for temporary medical foster care, long-term skilled nursing, or unconventional modes of treatment to facilitate the most informed choice. Ethics and legal consultation, team and family discussions, and thoughtful deliberations are warranted.

Ultimately, the parents' decision in both cases reflects their own values. These values seem to include, appropriately, concern about both the degree of physical burden on the infant's life and financial concerns related to treatment. Given the uncertainty about outcome, it is ethically permissible to forgo tracheostomy in one case and to proceed with invasive interventions in the other. When the results of a benefit burden calculus are nondeterminative, then we should support the parents' goals of care.

RYAN ANTEL COMMENTS

This case is framed against the backdrop of 2 families' decisions for and against withdrawal of life-sustaining treatment compelled by their different cultural and religious backgrounds. It asks whether bedside determination of resource utilization is a valid component of parental decision-making. Is honoring the parent's worldview, specifically in regard to available resources and expenses, something the physician can decide ad hoc?

The AAP reminds pediatricians that when caring for critically ill children, they should consider the value systems of patients and their families beyond simply quantitative indicators of prognosis.¹⁴ However, the AAP has also declared that decisions regarding the withdrawal of life-sustaining treatment in children should not consider the financial interests of the parents or the limited resources of the family.⁸ In the Amish context, the

AAP's directive to consider the family's social values in end-of-life decision-making directly conflicts with the obligation to discount concerns of financial means. The Amish believe in a strong separation between church and state and therefore refuse life and health insurance. Given limited or finite resources, the Amish must consider finances in the broader justice-driven context of the community.

Should we allow these parents to decide differently based on their values? I predict that this case would not have been troubling to the team had the parents defended their decision for withdrawal of care with arguments using the traditional and accepted bioethics lexicon. The parents could have argued that the burdens of medical and surgical treatment outweighed the potential benefit and, therefore, seemed to impose unnecessary harm on their child. Comfort care, they could have argued, seemed to be in their child's best interest. Had the argument been framed with only the individual in mind, it would have been more viscerally reassuring to the medical team; and they would have been able to honor the parents' values regarding the benefits and burdens of a life sustained by mechanical ventilation. Instead, the parents considered their limited finances and the impact that continued care would have on their broader community. The medical team was inclined to think purely in terms of the individual's medical burden, but the Amish parents challenged the assumption that burden is so narrowly defined.

Although the best interest standard is frequently used in determining the necessity for state intervention when parents refuse medical treatment, the primary criterion by which this is determined remains unclear. It is not clear that the best interest of the child should be the sole factor in decision-making; the interests of

children must be balanced against the welfare of others. Furthermore, any notion of best interest is intrinsically value laden. Instead it has been proposed that the threshold for state intervention should be the harm principle: does a parent's refusal significantly increase the likelihood of serious morbidity when treatment options have a high likelihood of success?^{16,17}

How is this case different from parental refusals of other lifesaving treatments? We are intolerant when Jehovah's Witnesses parents refuse a blood transfusion for their infant because they believe it will result in the loss of the child's salvation or when fundamentalist parents refuse chemotherapy for their child with leukemia because they believe God will heal their child without treatment. In these cases that seem black and white to the medical community, where the child is at significant risk of serious harm (ie, death), we call on the state to interfere. Although we grant parents significant freedom to make health care decisions for their child, we no longer believe that parental authority is absolute. Perhaps it is the invasiveness of the treatment and the projected burdens of prolonged mechanical ventilation at a long-term care facility and multiple surgeries that make this case fall within the gray zone. Here the benefit was not overwhelming enough to compel state intervention. Yet even this is arguable, for how could lifesaving tracheostomy with eventual decannulation not be overwhelming? We know that without treatment, the infant will die, as happened in this case. In contrast, infants who require tracheostomy placement and prolonged mechanical ventilation demonstrated average survival rates at 1, 3, and 5 years of life of 96%, 91%, and 90% respectively.¹²

MacIntyre has emphasized that different traditions constitute and mediate diverse visions of justice and

reason.¹⁸ This is in contrast to the liberal presumption that there exists a shared, ahistorical objective rationality, which can be used to resolve differences between competing socially embedded traditions. One's background and metaphysical commitments largely determine one's conception of justice and what constitutes reason. The enlightenment emphasis on individual rights shifted the moral unit of analysis from "persons-as-part-of-a-moral-community whose principle goal was a shared pursuit of the good life to persons-as-individual-rational-moral-agents whose principle goal was the free pursuit of self-declared interests or preferences."¹⁹ The Amish typify "persons-as-part-of-a-moral community" in ways somewhat baffling to our individualistic medical culture. Their very use of medicine is aimed at building community. Whereas modern medicine is inclined to think in terms of individuals, the Amish necessarily have to consider broader social implications. But how are we to consider the interest of an infant with an ambiguous future? An infant is not an asocial, autonomous, self-reliant agent but rather a dependent member of a particular moral community. As demonstrated by this case, physicians need to consider whether a community justice-based ethical vision should trump our traditional and supposedly objective standard.

JOHN D. LANTOS COMMENTS

There is an irreducible tension in moral philosophy between principle-driven approaches and case-based ones. Emerson famously wrote that "a foolish consistency is the hobgoblin of little minds."²⁰ Jonathan Sacks, former Chief Rabbi of the United Kingdom, thought otherwise when he wrote that "A world without values quickly becomes a world without value."²¹ Rigorous application of principles runs the risk of ignoring

the particularities of unique situations. Case-based approaches can lead to an anchorless moral relativism. These cases, and the insightful commentaries, highlight the need (and the difficulty) of balancing these 2 approaches to moral reasoning. Neither can ever be completely adequate by itself. The challenge is to recognize the particular elements of seemingly similar cases that allow ethical defensible variability in our responses. This presents a challenge to doctors and nurses because it appears to be ethically inconsistent and thus unjust. It seems that infants with similar conditions should be treated similarly. An infant's condition is never, however, just the medical condition. It also includes the cultural and religious values of the family and community within which the infant is born and would be raised. In complicated situations like these, when (1) the prognosis is questionable and (2) reasonable people disagree about the preferable course of treatment, a foolish consistency does not serve the best interests of children. Instead, deference to parents' values and preferences may appropriately tip the scales of justice.

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