

Infant With Trisomy 18 and Hypoplastic Left Heart Syndrome

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We present a case in which a fetal diagnosis of complex congenital heart disease and trisomy 18 led to a series of decisions for an infant who was critically ill. The parents wanted everything done. The surgeons believed that surgery would be futile. The parents publicized the case on social media, which led to publicity and pressure on the hospital. The case reveals the intersection of parental values, clinical judgments, ethics consultation, insurance company decisions about reimbursement, and social media publicity. Together, these factors complicate the already delicate ethical deliberations and decisions.

Some dramatic cases force doctors to reevaluate long-held ethical norms and ingrained patterns of practice. More commonly, however, ethical norms shift gradually and almost unnoticeably over time. Such slow shifts are usually the result of a combination of factors, including advances in medical technology and changes in social attitudes. In this ethics rounds, we present a case in which a fetal diagnosis led to a series of decisions for an infant who was critically ill with trisomy 18 and congenital heart disease. The case reveals the intersection of parental values, clinical judgments, ethics consultation, insurance company decisions about reimbursement, and social media publicity. Together, these factors led to complex ethical deliberations and decisions.

THE CASE

An infant born at 37 weeks' gestation had been antenatally diagnosed with trisomy 18. His ultrasound, done at 22 weeks' gestation, had also shown a well-balanced atrioventricular septal defect and a normal aortic arch. His parents were informed that the hospital

at which his condition was diagnosed did not offer surgical intervention for infants with trisomy 18. They transferred to a different hospital that was willing to offer cardiac surgery. At the second hospital, a prenatal ultrasound at 36 weeks' gestation revealed that the infant now had an unbalanced atrioventricular septal defect with hypoplastic left heart syndrome. The doctors then explained to the parents that, because of the trisomy, they would not offer surgery.

The parents requested that all possible life-sustaining therapies be provided. Thus, after delivery, a prostaglandin infusion was started, and the infant was stabilized, first with continuous positive airway pressure and then with intubation and mechanical ventilation. An echocardiogram confirmed the prenatal diagnosis, and the cardiothoracic surgeons told the parents that surgery was not an option. Instead, they recommended comfort care only. The parents declined comfort care. Over subsequent weeks, worsening heart failure developed. Enteral feeding was not provided because of risk of intestinal injury with ductal-dependent systemic blood flow;

abstract

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the infant was maintained on intravenous nutrition. The palliative care team arranged for the infant to be discharged from the hospital on prostaglandin.

Throughout the hospitalization, the parents continued to reiterate their desire for all life-sustaining therapies, including surgery. They described their situation on Facebook, leading to public attention in both traditional and digital media. When the infant was at 2 weeks of life, another medical center was identified that offered the first stage of surgical palliation. The parents faced a choice: (1) accept the risks of surgery and travel far from home, knowing that success was unlikely but that they had tried everything, or (2) take the infant home for hospice care. The parents opted for transfer and surgery. However, their insurance company declined coverage for transport, surgery, and postoperative care. An ethics consultation was requested.

Stephanie Kukora, MD, and Naomi Laventhal, MD, Comment

Trisomy 18 is an incurable, life-limiting condition, characterized by 1 or multiple anomalies, including dysmorphic appearance, kidney malformations, structural heart defects, abnormalities of the gastrointestinal tract, intellectual and developmental disabilities, poor feeding and growth, and abnormal breathing patterns or apnea. Trisomy 18 affects 1 in 5000 newborns.¹ It has a higher prevalence on antenatal diagnosis than among live births because of intrauterine fetal demise and elective pregnancy termination.²

Until recently, doctors thought that all infants with trisomy 18 would die during infancy. In 1996, these patients were reported to have a median survival of 3 days, with no survival at 1 year.¹ Today, however, we know that many infants with this condition can survive for years.³ Universal mortality was, it seems, the

result of both the medical condition and a self-fulfilling prophecy. When infants with this condition are not offered life support, most die. But if offered life support, survival rates increase.⁴ Authors of several studies of infants with trisomy 13 and 18 noted 1-year survival rates ranging from 8% to 25%.⁵⁻⁷ Ten percent survive >10 years.⁸ Surgical outcomes for infants with trisomy and congenital heart disease have improved.⁹⁻¹¹

Over the last 20 years, more children with these conditions are treated and survive.¹²⁻¹⁴ Even so, the majority of these children still die within the first year of life. All have severe cognitive and developmental impairment. Many have anatomic anomalies. Authors of existing cohort studies may report the outcomes of only a subset who received a particular therapy; for example, studies in which the authors evaluated surgical outcomes for trisomy 18 may be influenced by infants who were the sickest dying before surgery or being excluded for poor surgical candidacy. Likewise, treatments these patients receive at birth vary widely, which almost certainly influences length of survival.¹⁵ Thus, it is difficult to know how to counsel parents when they have an infant with a trisomy and other significant anomalies.

Despite the challenges of clearly characterizing the epidemiological outcomes of this population, the increased survival has sparked debate among ethicists regarding what options should be available to these infants, how we should weigh risks and benefits of these therapies, and who should make these decisions.^{2,15-23} This debate has led to relative consensus that a shared decision-making approach between physicians and parents should be employed for these decisions. We should avoid hard and fast rules and, instead, individualize decisions on the basis of both the specifics of each

patient's condition and consideration of the parents' goals and values.

Shared decision-making entails that parents and physicians should collaboratively choose between ethically permissible options on the basis of parents' values and available medical information.²⁴⁻²⁶ Values provide a context in which an outcome can be framed as good or bad.²⁷

Parents' and doctors' values shape their perceptions of different outcomes. When survival is improbable or impossible, outcomes such as having more time with their living child, avoiding suffering, having an opportunity to hold, staying hopeful or faithful, or being a good parent may determine their choices. The same event, such as a child dying on the operating table during surgery, may be perceived by parents as better than having their child die while receiving comfort care. Surgeons might perceive that same outcome as the worst possible one.

Many professionals have negative attitudes toward infants anticipated to have severe impairment. Medical literature has been focused on the high morbidity and mortality of these conditions and the degree of impairment typical for the population, with concomitant emphasis on the invasive, painful, or undignified aspects of early intensive care. Physicians rarely see these children in happy families. Parents of these patients, by contrast, report that their children have a good quality of life.²⁸

Christian Vercler, MD, Comments

The decision by a surgeon that a patient is not a candidate for an operative intervention places a definitive limit on parental choice. Surgeons are uniquely empowered to make such refusals. Intensivists feel less empowered to say "no" to parents.²⁹ In this case, many surgeons

refused to operate, but one was apparently willing.

When a surgeon states that a patient is “not a surgical candidate,” the surgeon is making a judgment that balances facts and values and includes concepts that may be opaque to the nonsurgeon. It may be that the proposed operation is anatomically impossible. It may be that, physiologically, the operation will not make the person better. It may be that the surgeon herself does not feel confident that she can bring the patient safely through the operation. The surgeon may feel that the goal of the operation is inappropriate or unachievable. Because the factors that influence this decision are not necessarily clear to all involved parties, such a decision can trigger concerns that the decision is motivated by judgments about the quality of life rather than the chance of surgical success.

The statement that a patient is “not a surgical candidate” is a performative utterance. The statement changes the circumstances of the person it describes. Other examples of performative utterances are when a police officer says, “You are under arrest” or when a priest declares, “I pronounce you husband and wife.” In this case, the determination that the patient was not a surgical candidate led the insurance company to refuse to fund the operation.

That surgeons are granted the authority to decide when an operation will or will not be performed reflects recognition of the skill and judgment exercised in deciding whether the benefits of operating on a patient outweigh the risks of anesthesia and surgery. Surgeons spend tens of thousands of hours learning to make these decisions. The prudence required in surgical decision-making is inseparable from the performance of the operation.³⁰ Surgeons hold

themselves personally accountable if a patient has a bad outcome.³¹ Parental permission does not legitimize an operation that cannot achieve an intended goal.

In this case, there was no disagreement about the fact that the operation would not be able to achieve its intended goal. The goal of the first stage of the 3-stage palliation of hypoplastic left heart syndrome is only to prepare the cardiopulmonary anatomy and physiology for the second- and third-stage operations. Even the surgeon who was willing to do the first-stage procedure believed that this child would not survive to undergo the second or third stage. The issue, thus, was whether the goal of performing the operation to allow the parents to say that they had “done everything” is a legitimate goal.

Janice Firn, PhD, Comments

After the decision was made that the patient was not a surgical candidate, the parents requested ethics consultation. In the conversation with the ethics consultation team, the parents expressed concern that the decision not to offer surgery was based on the surgeons’ personal bias toward persons with trisomy 18 rather than on medical reasoning.

In the discussion with the ethics service, the parents identified the following goals for their son and their family: (1) do everything to have their son live at home; (2) pursue all available therapies to prolong their son’s life, including cardiac surgery, even if that means transferring to another facility for the surgery; and (3) be close to their social support network and their other children.

They believed that he could beat the odds. They were quoted as saying, “[We’re hoping] that [he] is able to grow and come home with us and we’re able to grow and interact with our kids, our family, our friends – just watch him grow at a place other than in the hospital... We absolutely hope

and believe that [he is] going to defy the odds and that he will live for a long time with us.”³² At the same time, they were grateful for every day that he was alive and wanted as many such days as possible, noting, “As I begin this day I’m thankful for another day with [him]. Thankful he’s so peaceful and comfortable. Thankful he’s so awake and responsive to my voice. I love this baby more than anyone can imagine.”³³

His parents believed that their values should prevail over those of most doctors. His mother said, “I do a lot of praying and talking to the doctors and the nurses and hoping that somehow we can change their mind... I’m hoping that it is possible. I’d like to take my son home”³⁴ and “It’s a very risky surgery. But we have someone...that is actually willing to do the surgery and wants to get [him] there now.”³⁴

The Ethics Committee Decision

After reviewing the cardiac surgeons’ decision to not offer surgery, the ethics committee determined that it was made on the basis of the medical condition of the patient and was not the result of bias regarding trisomy 18. They felt that any child with similar medical status, even in the absence of trisomy 18, would be denied surgery. The ethics committee felt that the cardiac surgeons’ decision was ethically permissible. They wrote, “When an intervention portends disproportionate burdens relative to the intended outcome, physicians are under no obligation to initiate treatment, even if requested by parents.” The ethics committee referred to and relied on the institution’s nonbeneficial treatment policy in its recommendations. Consistent with the official policy statement of the American Thoracic Society,³⁵ the institutional policy states that when a medical intervention is deemed to be medically futile, physicians are under

no obligation to initiate or continue such treatment, even if requested by the patient or the patient's family or representative(s). An intervention is considered futile when it satisfies all of the following conditions: (1) the patient's condition is terminal and incurable, (2) the intervention is not required for relieving the patient's discomfort, and (3) the intervention offers no reasonable medical benefit to the patient and serves only to postpone the moment of death.³⁶

Nevertheless, the ethics committee also supported the parents' right to transfer their child to another institution. They wrote, "When differences in perception of benefits and risks between parents and medical teams occur, after careful deliberation and conversation to ensure consistency in comprehension and underlying facts, parents should be given the opportunity to secure the services of another physician or hospital and be supported in their efforts to do so." This, too, was based on the American Thoracic Society recommendation that, when there is intractable conflict, teams should offer the option to transfer care to another institution if an accepting institution can be identified.

Media and Social Media Involvement

The case garnered media attention. The patient's Facebook page, created by his mother, was followed by tens of thousands of people.^{37,38} Multiple news stations were following the story as well as several advocacy groups. A friend of the family created a GoFundMe page, which was shared >2800 times and raised >27 000 dollars.

Partly as a result of the publicity, another institution was identified that would accept the patient in transfer. When the parents' insurance company declined to cover the costs, a stranger donated 39 000 dollars to pay for the transfer to the accepting institution.³⁹ The family was also able to apply and qualify

for the Children's Special Health Care Fund to cover costs.

Bryanna Moore, PhD, Comments

This case did not reach the level of national news, but what if it had? What if the family's Facebook page had attracted hundreds of thousands of followers, or what if they had raised millions of dollars? What if the President had decided to tweet about this story? Turning to digital media can seem like the best or only way for frustrated parents to advocate for their child. It does not always work, but it changes the debate from a private and personal one to a public one, sometimes with unintended consequences.

Once digital media get involved, if things go viral, relatively private disagreements about futile treatment can be coopted by third parties for personal and political purposes. This case could easily have transformed from a discussion about what was best for the infant to one about whether doctors were biased against infants with disabilities or about whether health care organizations abuse their power. Such discussions may or may not have furthered the parents' goal of getting surgery for their infant.

Clearly, the voices of digital media are not necessarily voices of respectable moral authority or reason in such debates. But they are powerful. Clinicians and ethicists involved in these cases might ask themselves: Would our reasons for refusing a parental request stand up to mass publicity? Would we be comfortable if 50 000 people knew what we said to a family behind closed doors? The test of public scrutiny can lead to more accountability. Interventions should never be offered solely as a result of mounting media or public pressure. But, in situations of clinical and ethical uncertainty, a test of public scrutiny may be an ethically appropriate way to check how

committed providers are to a given recommendation.

Digital media had an effect on this infant's journey. It enabled his story to spread. If this story had not been picked up by the press, a third hospital may never have stepped in and offered palliative surgery. The relatively mundane act of people clicking the "like" and "share" buttons shaped this infant's short life and forever changed this family's story. Clinicians and health administrators must be prepared for the ways that private conversations and decisions may quickly be subject to public scrutiny and judgment in the court of public opinion.

Case Resolution

When the patient was 5 weeks old, the insurance company changed its decision and approved payment for transfer and treatment. The patient was transferred with an agreement that he could only return to the referring hospital for care when he had completed postoperative recovery with only controlled and/or mild heart failure. After transfer, the patient's mother remained at his side, away from her home, job, and 3 other children, who were cared for by their father. He underwent surgery at 8 weeks of age. Postoperatively, his cardiac status worsened. After 6 weeks of intensive postoperative support, his parents and care team reached consensus that there was no chance of survival. His parents requested that he return to the initial center for end-of-life care, but he was too unstable for transfer and died at 14 weeks of age after transition to comfort care.

After he died, his mother stated, "I'd do it all over again....I had three wonderful months with a sweet little boy....The heart surgery was successful. It was other complications with his other organs....If we'd have taken him home without it we might have gotten a day.... I think he was given to us for a reason. Special

children are given to the strongest parents and I think he was given to us for a purpose.”³⁷

John D. Lantos, MD, Comments

Conflicts about medical futility have troubled patients, parents, professionals, judges and policy makers for decades.⁴⁰ In recent years, parents’ ability to publicize such cases using social media has made the controversies even more complicated.⁴¹ This case illustrates the fundamental issue in such cases. Treatment of this infant clearly prolonged his life. Without intubation, mechanical ventilation, parenteral nutrition, and prostaglandin, he would have died within days. Instead, he lived 14 weeks. His mother thought that the efforts to save his life were ethically appropriate and that his life had a purpose. At least one doctor was willing to offer surgery. Many doctors and policy makers might disagree and argue that we only prolonged the infant’s dying process and subjected him to numerous painful procedures at great expense when the outcome was clearly foreseeable. In the United States today, however, both the court of public opinion and, in most cases, the judiciary would side with the parents. In doing so, they affirm the value of each life, no matter how short or diminished by illness that life might be. That is a difficult value to oppose.

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