

# When a Child Needs a Transplant but Lacks Familial Social Support

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We present the case of a 19-month-old boy with complex congenital heart disease. His single father is skeptical of traditional medicine and does not offer the social support needed to make heart transplantation successful for his son. After the father demonstrates commitment to transplant success and provides enhanced social support, doctors place the child on a Berlin Heart (a biventricular assist device) as a bridge to transplantation and list him for transplant. When the child is matched to a donor heart, the father refuses transplantation, despite that it is the child's only chance for survival. His doctors report the case to child protective services, but they decline to take protective custody. The father then changes his mind and asks that the child be put back on the waiting list for transplant. By this time, the social supports the father implemented are no longer in place. This case raises a number of issues. First, should courts order heart transplantation when doctors believe that it is in the child's best interest and parents do not consent? Second, once parents refuse a transplant, can they change their minds? Third, if there are uncertainties regarding whether the child has the social support to make transplantation successful, should the child be relisted? Finally, should a child who is not currently a transplant candidate but who may become one in the future be supported with ventricular assist devices?

Social support is critical for the success of a heart transplant. This is especially true for children, who rely on their families to provide their immunosuppressive drugs and bring them for appropriate follow-up care throughout their childhood. There are more children waiting for a heart transplant than there are available donor hearts. Many die on the waiting list. Now, with both long-term extracorporeal membrane oxygenation and ventricular assist devices (VADs) (including the Berlin Heart), patients with failing hearts can be kept alive for months or years as a bridge to transplantation. Transplant teams perform a social support assessment before listing a child for transplantation and placement on a

VAD. But if a child's social support system changes during the (sometimes lengthy) period after listing, should the child continue to be listed? In this ethics round, we consider a case in which a child who was initially listed for transplantation was delisted when his parent refused a well-matched donor heart. There were also changes in the child's parental social support system. Doctors faced a decision about whether to relist him in light of a family situation that disadvantaged him with respect to the social support needed for transplant success.

## THE CASE

Aiden is a 19-month-old boy with complex congenital heart disease.

## abstract

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Ms Mabel conceptualized the ethics issue in this case and the idea of drafting a manuscript and drafted, critically reviewed, and revised the manuscript; Drs Ahmad, Harrison, Blume, and Lantos drafted, critically reviewed, and revised the manuscript; Dr Bester conceptualized the idea of drafting a manuscript and drafted, critically reviewed, and revised the manuscript; Dr Boyle conceptualized the idea of drafting a manuscript and critically reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Aiden's mother died from cancer after opting for naturopathic treatment. Aiden's father, Tim, is skeptical of traditional medicine. Curative surgery may have been an option if the heart condition was discovered early, but Tim did not bring Aiden for timely preventive well-child visits. The condition was only discovered later when Aiden became severely symptomatic and required hospitalization. Heart transplantation is now Aiden's only chance for long-term survival.

The medical team was initially concerned that Aiden's social situation could compromise successful transplantation. Tim rarely showed up to family meetings, declined to immunize Aiden's twin brother (a necessary step in bringing Aiden, who would be on immunosuppressive therapy, home posttransplant), and often had young teenagers or adolescents from the neighborhood watch Aiden's twin while Tim worked full-time. The medical team worried that this suboptimal social situation would continue posttransplant.

However, Tim ultimately began attending family meetings more regularly, promised to immunize Aiden's twin (Aiden was immunized in the hospital), and hired a full-time nanny to provide consistent child care. With assurances that Tim (or the nanny) would take Aiden to follow-up appointments and provide medications regularly, the medical team listed Aiden for a heart transplant and placed him on the Berlin Heart, a VAD designed to bridge children to transplant. Aiden's Berlin Heart is an external implant, with mechanics housed in a unit that is roughly the size of a dishwasher, limiting Aiden to living in the hospital.

The Berlin Heart is not a destination therapy but is used to extend a pediatric patient's life while he or she waits for a heart transplant. The longest a patient has survived

on a Berlin Heart is 902 days.<sup>1</sup> Complications include stroke, bleeding, infection, hepatic dysfunction, hepatic injury, and pancreatitis.<sup>2</sup> When the Berlin Heart was considered, the medical team explained to Tim that it represents a temporary measure until a donor heart becomes available, and Tim agreed with this plan.

Three months later, a match became available. Tim declined transplantation, saying he wanted to do more research into alternative treatments. Additionally, Tim had stopped attending family meetings and informed the health care team he had not immunized Aiden's twin and no longer had consistent child care. Tim was able to afford the nanny but felt her presence was intrusive. The county's child protective agency was informed of Tim's decision but declined to take custody of Aiden and indicated it would not revisit its determination. The medical team redirected the donor heart to another patient and moved Aiden to inactive status on the transplant waitlist.

The medical team feels the Berlin Heart is not a long-term option and requests an ethics consult. On the Berlin Heart, Aiden would ultimately experience a complication leading to his death, and the team worries about quality of life. Successful transplantation could extend life and improve quality of life, whereas Berlin Heart removal would cause Aiden to die quickly. Tim expresses remorse for turning down the transplant, asks that Aiden be relisted, and promises to provide the necessary social support. The team worries that, on the basis of previous actions and present social circumstances, Tim will not be able to follow through. Should Aiden be relisted for transplantation?

#### **Ms Mabel and Drs Ahmad, Boyle, and Bester Comment**

In pediatric transplant cases, 2 distinct ethical frameworks are

relevant: pediatric ethics and transplant ethics. The fact that these 2 frameworks sometimes support mutually exclusive options is highlighted in this case; the competing moral values inherent in these frameworks (as well as practical constraints) can impede achievement of an optimal result concordant with both. In a situation like Aiden's, we would recommend prioritizing transplant over pediatric ethics principles by declining to move Aiden to active status on the transplant waitlist.

Under a pediatric ethics framework, health care professionals ought to promote the best interests of the pediatric patient.<sup>3</sup> This standard can variably take the form of an ideal of what is best for the child, a standard of reasonableness when the literal best thing for the child is unachievable, or a threshold below which intervention becomes imperative and considers the child's immediate and future interests.<sup>4</sup> Although this standard affords parents wide latitude in making medical decisions on their child's behalf, parental authority is not unlimited, and the best interest standard functions as both a guiding and a limiting principle.<sup>5</sup> In essence, the best interest standard asks us to consider the feasible medical options and choose the 1 that most promotes Aiden's various interests. Those options that undermine his interests are ethically out of bounds.

Considering Aiden's interests, we note that transplantation would extend and improve Aiden's quality of life and best promote both his immediate and long-term interests. Although children on Berlin Hearts live for a limited period of time, heart transplant recipients between 1 and 5 years of age survive for a median of 16.8 years, which median increases to 20.6 years if the recipient survives the first year posttransplant.<sup>6</sup> In addition to providing Aiden with a much longer life span, successful

transplantation would also improve his quality of life, allowing him to go home and experience a normal childhood.

At the same time, the practical consideration of whether Aiden will have the posttransplant social support necessary to optimize his chances for success is ethically relevant. Such support includes regular follow-up medical appointments, caregiver presence during and immediately after transplantation, and strict adherence to lifelong immunosuppressive drugs, which in pediatric cases becomes the responsibility of parents to enforce. Importantly, poor social or familial support and nonadherence to previous therapies are relative contraindications for heart transplantation.<sup>7</sup> Tim's reversal of Aiden's plan of care by declining transplantation, historical failure to bring Aiden to well-child visits, nonattendance at scheduled family meetings, skepticism of traditional medicine, and lack of consistent caregivers in the home translates into a real risk that Tim will fail to provide Aiden with immunosuppressive drugs or bring him for follow-up appointments. This nonadherence, or lack of therapeutic alliance, could prove fatal to Aiden. Nevertheless, the best interest standard suggests that attempting transplantation is the most ethically appropriate course of action. Without transplantation, Aiden will most certainly die. With transplantation, he has a fighting chance at life, if the transplant succeeds.

However, under a transplant ethics framework, the transplant team cannot only think about Aiden's best interests. Rather, health care professionals have concurrent obligations to the potential organ recipient, the organ donor, and other candidates on the transplant waiting list. Currently, >350 children in the United States aged 0 to 17 years are waiting for a heart transplant.<sup>8</sup> Each

of these children, like Aiden, is in limbo, hoping to receive a suitable organ match that could save his or her life. Because transplantable donor hearts represent a scarce resource, health care professionals have an ethical obligation to be judicious in their allocation.<sup>9</sup>

In Aiden's case, Tim has demonstrated that he may not be able to provide adequate posttransplant social support and adhere to follow-up medical care. If adequate social support is not in place, the heart transplant may not only be unsuccessful for Aiden but may also cause a heart to be diverted from another potential recipient for whom it could have been successful. Such an unjust result (no one benefitting from a viable donor heart) is not ethically supportable under a transplant ethics framework. In the context of the scarcity inherent in organ transplantation, the transplant center must weigh the interests of many deserving patients seeking the same transplant organs and services as well as the center's obligations to donors and their families. Although it may not be possible to do what is in the best interests of all, it is ethically most supportable for the transplant center and medical team to do the best they can to serve the interests of stakeholders to the greatest extent possible. This commits them to following an approach that maximally serves the interests of all patients and donors while potentially making trade-offs and placing limitations in individual cases.

This presents a difficult moral dilemma; whichever choice is made will leave something of moral importance undone. Because clinicians must act, we have to examine reasons for choosing 1 option over the other.

Despite Tim's current promises, his past actions indicate a strong possibility that he will not provide the social support necessary to optimize success of the transplant.

He went back on each of his initial commitments (family meetings, immunization, and reliable child care) as well as his agreement to consent to transplantation after placement of the Berlin Heart. Although the door should not be permanently closed on Tim demonstrating a renewed (and, importantly, reliable) commitment to providing adequate social support, at this time, the health care team's obligations to other individuals on the transplant list and to a potential donor outweigh its obligations to Aiden. The team could once more petition the state's child protective services to reconsider its decision and to take custody of Aiden or seek a court order for the agency to do so to ensure social support after transplantation. However, in the absence of such governmental action, it would not be ethically supportable to move Aiden to active waitlist status and simply hope that social support from Tim materializes. It would still be ethically incumbent to provide the best care possible to Aiden (medically, socially, and developmentally) while Aiden remains on the Berlin Heart in the forms of medical care, physical therapy, occupational therapy, art therapy, and music therapy as well as palliative and hospice care when they become necessary.

In Aiden's case, the health care team can be capable of and willing to provide the best medical care, but his health and life depend on whether someone else provides the social support he needs to make transplantation successful. There are, therefore, limits to doing what is in the child's best interests in the context of transplantation, which can be difficult for care providers, especially those who treat children, to grapple with.

#### **Drs Harrison and Blume Comment**

In the United States, allocation of solid organs among potential

recipients on the wait list is addressed at the national level. Selection of patients to join the wait list is assigned to local transplant teams. With limited national guidance, local teams must balance the interests of individual patients with stewardship of donor organs.<sup>10</sup> In the context of an ethics consult regarding Aiden's case, we reflect on 3 issues that are amenable to action by the local transplant team.

### *Assessing and Promoting Net Benefit for the Patient*

Patient selection in pediatric transplant begins with assessing whether transplant is a preferred therapy for a patient. The transplant team balances the benefits of the therapy against its risks. For Aiden, transplant surgery offers both a longer life and an improved quality of life. For children who receive a transplant between 1 and 5 years of age (25% of whom are on mechanical support), median survival is 21.9 years, and 1-year survival is >90%. Transplant is the definitive therapy for a child on a Berlin Heart VAD, and a parent's decision to refuse would almost certainly result in Aiden's death. In addition, because the Berlin Heart currently has no portable driver, patients in the United States must stay in the hospital. Still, risks and burdens of transplantation include the need for medication compliance every 12 hours for life along with frequent appointments and procedures. Complications after heart transplant include rejection, infection, lymphoma, and coronary artery disease. In particular, if a recipient does not receive medication regularly, the transplanted heart is at risk for rejection, coronary disease, and death.

In Aiden's case, the transplant team previously listed Aiden when it appeared that Aiden's father and sitter together had the ability to provide a stable medical home supporting regular posttransplant

care. Now that Tim has turned down the offer of a donor heart and ceased to employ the nanny consistently, these foundations for a successful transplant are called into question. Tim did accept mainstream medical technology in consenting to the Berlin Heart; however, his reluctance to immunize the twin reinforces the concern that he may not accept the traditional medicine that will be needed for Aiden's survival. These are psychosocial risks that can constitute contraindications to relisting.

Contraindications like these are not within a child's control, and it would be unfair for Aiden to lose the chance for a beneficial transplant unless all reasonable efforts had been made to address them. Importantly, then, in addition to objectively assessing risk factors for transplantation, the team must also consider how to minimize these risks while the patient is waiting and after the transplant.

The team must find a way to align with Tim for shared decision-making about the value to Aiden of having the transplant and the ways to support success. We would recommend open conversations with Tim about several concerns:

- Coping and support. To what extent has Tim's behavior been affected by his grief at the recent loss of the children's mother as well as the stresses of caring for a chronically ill child? Increased psychological supports for Tim are likely required. Also, if Tim himself seems unlikely to provide a stable, medically adherent home with a second adult available as a support, are there family members or others who could be educated about the decision-making to help Tim in the moment of organ offer as well as with care beyond the hospitalization?
- Information and understanding. How well does Tim understand the pros and cons of transplant

for Aiden, compared with any conceivable alternatives that he has expressed a desire to explore? Does he understand that hospital discharge is not possible? Exploring Tim's ideas about immunization is another critical pathway to understanding his views regarding traditional medicine. If a transplant does not appear likely, what would be Tim's goals of care for Aiden?

These discussions may enhance Tim's understanding of his son's prognosis and the role of transplant. They should also aid the team in understanding and supporting him. If the team can find common ground to build on with Tim, along with a second adult to help with Aiden's care, then relisting may be appropriate.

### *Responding to Parental Refusal of Recommended Transplant*

Competent adults have the right to refuse unwanted medical treatment. Parents can exercise this right on behalf of their minor children, although the right is not unlimited. Shared decision-making between parents and clinicians is always ideal; however, there are times when differing judgments cannot be reconciled. These situations are particularly challenging when parents refuse recommended life-sustaining treatment. In general, life-sustaining treatment can be declined when its burdens outweigh its benefits to the child.<sup>11</sup> Clinicians should defer to good faith judgments made by loving, engaged, and well-informed parents when the net benefits of the treatment are ambiguous or uncertain or the risks of harm to the child are not serious, imminent, or clear.<sup>12,13</sup>

A commonly accepted example of such clear and imminent harm is found when parents refuse a potentially life-saving blood transfusion for a young child on religious grounds; in

such circumstances, clinicians are generally thought to be ethically justified in seeking court authorization for a medically necessary transfusion. In situations more analogous to heart transplantation, clinicians often defer to parental judgment, although there is debate within the profession. Relevant examples include parental choice of palliative care in lieu of surgeries for hypoplastic left heart syndrome<sup>14,15</sup> or bone marrow transplant for severe combined immunodeficiency.<sup>16</sup> In each context, the treatment is likely to be life-saving; however, the procedures are onerous, and the prospect of long-term survival with an acceptable quality of life is uncertain. In the ethics consult for Aiden, comparisons like these should be considered.

The “clear harm” standard is generally consistent with legal standards for state intervention. In Aiden’s case, the local child welfare agency has declined to be involved. State court may remain an option to seek permission for the hospital to perform the transplant surgery and provide related care as well as an order for the state to find a medical home. Before taking this route, however, it would be important to consult the child protection team and assess the possible psychosocial harms to the patient and family as well as the certainty of actually realizing the desired long-term stability and other benefits, even with judicial support.

#### *Promoting Justice for All Patients Seeking Listing*

The pool of donor organs is a public resource that must be distributed fairly. The Organ Procurement and Transplant Network has identified 3 general principles to guide organ allocation and listing decisions: maximizing the overall net benefit to organ recipients, promoting justice, and showing respect for persons.<sup>10</sup> With respect to listing,

considerations endorsed include psychosocial factors affecting patient adherence and “ethical rules” such as honesty. Although some clinically focused professional guidance is available to local teams seeking to implement this responsibility,<sup>17</sup> there is a dearth of both descriptive research and normative analysis regarding the task of balancing benefit and justice considerations. Important work remains to be done at a national level. Meanwhile, we recommend measures that could be taken by the local transplant team to address some fundamental and procedural aspects of justice in Aiden’s case and others.

A fundamental element of fairness is that “like cases” be treated alike: patients who are similarly situated with respect to listing criteria (eg, with a similar likelihood of benefitting from transplant) should have the same chance of being listed irrespective of location. Criteria should be evidence based and not affected by bias or other ethically irrelevant factors.<sup>18</sup> To promote consistency on these dimensions from center to center, we would encourage the transplant team to consult broadly with colleagues at other centers on difficult cases like Aiden’s and to seek to build and publish a national professional consensus on challenging common issues. Methodologies used to inform the evolution of professional opinion in the case of hypoplastic left heart syndrome<sup>19</sup> could be useful. Public input would be highly desirable.

In addition, we would recommend other measures be established within the local center to improve the fairness and public accountability of listing decisions. Regulations already require that center patient selection criteria be established in writing and made available to the public. If patients are denied a place on the list, they and their families should be informed in writing of the specific reasons supporting that

judgment; ideally, the reasons would be ones that the public could accept as relevant, and other procedural measures promoting accountability would be included.<sup>20</sup> Teams could also promote fairness by conducting research on the variability of listing decisions from center to center,<sup>21</sup> soliciting community involvement in debating contested issues, or establishing monitoring boards to review listing decisions.<sup>18</sup> We trust that the ethics service consulted on Aiden’s case includes community members among its ranks.

#### **Dr Lantos Comments**

Competent adults often change their mind about what treatments they want or do not want.<sup>22</sup> They are allowed to do so and do not forfeit their right to life-sustaining treatment because they once said that they did not want it. Parents have the same right. In this case, the problem arises not simply because the dad changed his mind but because of the circumstances. His shifting preferences were coupled with a lack of commitment to the treatment and follow-up that his child needed. Such nonadherence would likely doom a transplant to failure. Because organs are scarce and because many people die waiting for a heart, transplant centers have an obligation to maximize the likelihood of success. As noted, this father has to show that he can be compliant with a complicated medical regimen, and that he is committed to following that regimen, before his child should be eligible for transplant. The decision, then, about whether to continue life-sustaining treatment turns on a probabilistic assessment of the likelihood that the father is truly committed. Given the hope of successful treatment with a heart transplantation, it makes sense to err on the side of generosity and to continue life support, even if that means that the child will be in an ICU for months.

All of the cases in *Ethics Rounds* are based on real events. Some incorporate elements of a number of different cases in order to better highlight a specific ethical dilemma.

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## ABBREVIATION

VAD: ventricular assist device

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