Public Appeals Challenging Criteria for Pediatric Organ Transplantation

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In this article, I review the ethical issues that arise in the allocation of deceased-donor organs to children and young adults. By analyzing the public media cases of Sarah Murnaghan, Amelia Rivera, and Riley Hancey, I assess whether public appeals to challenge inclusion and exclusion criteria for organ transplantation are ethical and under which circumstances. The issues of pediatric allocation with limited evidence and candidacy affected by factors such as intellectual disability and marijuana use are specifically discussed. Finally, I suggest that ethical public advocacy can coexist with well-evidenced transplant allocation if and when certain conditions (morally defensible criteria, expert evidence, nonprioritization of the poster child, and greater advocacy for organ transplantation in general) are met.
In the United States, deceased-donor organ allocation is regulated by
the Organ Procurement and
Transplantation Network (OPTN).
As with other systems of organ
allocation, the OPTN rules seek to
balance utility (making the best
possible use of a donated organ) with
justice (ensuring equitable access to
a scarce resource). The fundamental
principle of respect for persons
dictates that these allocation criteria
be fair by “giving everyone an equal
opportunity to receive an organ when
they are in need.” Factors such as
waiting time, degree of
histocompatibility, severity of illness,
donor quality, recipient age, and
distance between the donor and
potential recipient may all be factored
into the system, with different
weighting and calculation of these
factors depending on the organ type.

Even with a well-resourced and well-
regulated allocation system, there is
a gap between supply and demand,
and 20 people die in the United States
every day while waiting for an organ
transplant (on the basis of OPTN data
as of July 2019). Some have described
this as a “lifeboat” scenario because
only a portion of all people in need
can be saved. Organ allocation has
also been described as a “zero sum
game because changes that give some
individuals or groups of people
priority for transplant necessarily
disadvantage others who are waiting
for the same organs. Because of the
extremely high stakes, the need to
maintain the trust of the public, and
the complexity of a national system
for organ sharing, it is important to
have “objective and enforceable
rules” that are open to changes once
better evidence becomes available.

In the age of social media, the rules
and their application can come under
public scrutiny when parents or
family members launch a public
appeal for their child to receive
a transplant. Is it fair for parents to
make these public appeals on behalf
of their children? Should OPTN rules
be appealable through either court
decisions or public pressure? How
should the media and media
consumers respond to these
campaigns? By discussing the cases
of Sarah Murnaghan, Amelia Rivera, and
Riley Hancey, I will attempt to answer
some of these questions.

**SARAH MURNAKGHAN: CHALLENGING THE EVIDENCE ON ALLOCATION**

Sarah Murnaghan’s case was one of
the most recent successful public
advocacy campaigns. Sarah was
10 years old when her lungs were
failing because of cystic fibrosis, and
she was activated on the transplant
waiting list. Because of her size and
the surgical techniques available, her
transplant team felt that she could
benefit from either pediatric or adult
donor lungs, but the OPTN policy at
the time determined that children
younger than 12 could only access
adult-sized organs after they had
been offered to adolescents and
adults in the same geographic
allocation zone. At the time, there
were ~40 such adults in the local area
waiting, so the chances of her
receiving adolescent or adult donor
organs were minimal. The policy did
not allow for individual policy
exemptions.

Sarah’s mother, a former public
relations professional, used her skills
and connections in the public
relations community to launch
a public appeal to change the
allocation rules. A Change.org petition
generated 373 000 e-signatures to
support Sarah and gained the
attention of an attorney who agreed
to represent the family on a pro bono
basis. The court’s decision ordered
Kathleen Sebelius, the US Secretary of
Health and Human Services at the
time, to temporarily suspend the
“under-12 rule” that kept Sarah from
competing for adult lungs. Sarah
received 2 sets of lung donor organs
within the next few weeks and is
reportedly doing well post
transplant.

Sarah’s case made national headlines.
Some celebrated that the advocacy
was successful, but critics were
concerned that Sarah’s endearing
story and slick publicity campaign
advantaged her in a way that other
waiting list candidates were not and
that the decision to suspend the
existing policy was done on the basis
of public opinion rather than medical
expert testimony. As leading
transplant physician, Giuliano Testa,
stated in a commentary on the case,
“Although we rejoice about the return
to health of a young child, we cannot
say that justice was done in this
case.”

The action of Sarah’s parents was
evidently understandable. The
responsibilities and bonds that we
have to our children are necessarily
stronger than those we have to
others. In a life-threatening
scenario, a parent would naturally do
all that is necessary to save their own
child, even if they are aware that
others are also in need of saving. But
should the courts (both legal and
public opinion) bow to the story of
a single child or a single family?

When policy changes benefit only the
poster child, they are difficult to
ethically support because there are
likely no morally relevant criteria to
advantage one sick child over another
who is equally sick. But single stories
do have the power to promote
changes that affect all similar
children, as has been demonstrated in
the stories of individual refugees that
have given a face to a crisis and have
changed immigration policies
worldwide. Although the initial
court decision benefitted only Sarah
(and another child waiting for
a transplant at the same center), the
long-term effects of their advocacy
changed the allocation rules
permanently. As Stuart Sweet,
a pediatric lung transplant physician
and OPTN board member, reflected,
“On day one of this story, I think I said
it’s a zero sum game and we have
a policy and we shouldn’t change it…”

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I think the system wouldn’t have changed as fast if the Murnaghans hadn’t gotten involved.”12

The evidence, or lack thereof, for the under-12 rule seemed to support the changes that Sarah’s parents fought for, but the wisdom of allowing courts to make emergency decisions to transplant allocation procedures have been questioned in other cases. An emergency change to lung allocation policy was instituted after a court challenge in 2017, changing allocation from one based on donor service areas to one that would offer organs within a 200-nautical-mile radius of the transplant center (crossing over donor service areas). An analysis by Puri et al13 revealed that after this change, there was no difference in 30-, 60-, or 90-day mortality of patients at their center (so no overall improvement in utility), but the organ retrieval costs increased significantly, from $34,000 to $70,000 per organ.

Additionally, there was a significant increase in the mean ischemic time, from 204 to 244 minutes, meaning that the organs spent more time “on ice” instead of in the body of the recipient, which could adversely affect long-term survival.13 The authors of this study stated as follows:

The issues associated with equitable organ allocation need to be weighed in balance with other parameters. How they balance out should be for the transplant community and not the courts to decide since legal experts stipulating these changes are unlikely to understand the complex environment and the myriad of down-stream effects.13

If the Murnaghan case is viewed only as the story of a single child and her family’s ability to fight for her from a relatively privileged position, it could be seen as a work-around to the well-intended efforts of the OPTN to make difficult allocation decisions. But when viewed as the story of a single child who brought to light weaknesses in the evidence for one particular rule, it speaks to the power of narrative and how it sometimes takes a single story to effect a change that is fair and necessary.14

**AMELIA RIVERA: PUBLIC ADVOCACY IN THE AGE OF PUBLIC SHAMING**

Amelia Rivera was a 3-year-old girl with Wolf-Hirschhorn syndrome in 2012 when her parents met with the transplant team at Children’s Hospital of Philadelphia (CHOP) to discuss the possibility of a kidney transplant.15 According to her mother, Chrissy’s, blog, Amelia was denied access to a transplant at CHOP because she was intellectually disabled.16 The Riveras argued, “We are in the year 2012 and my child still does not have the right to live, the right to a transplant, because she is developmentally delayed.”16 When the case became public, a Change.org petition garnered >51,000 signatures.17 The family later partnered with CHOP in a joint statement, Ms. Rivera was permitted to donate a kidney to her daughter, and Amelia is reportedly doing well.18 The joint statement suggests that what the transplant team thought they said and what the family thought they heard were different:

While we can unequivocally state that we do not disqualify transplant patients on the basis of intellectual ability, and have a history of transplanting children that have a wide range of disabilities, this event underscores the importance of our responsibility to effectively communicate with families.19

While the debate over whether children with intellectual disabilities should be eligible for transplant has continued in the years since Amelia's case, it is increasingly clear that children with intellectual disability can and do benefit from organ transplants. Children with developmental disabilities contribute to their families and communities, and we have long abandoned the idea that those with financial or intellectual gifts are somehow more worthy of receiving lifesaving care over others. Children with intellectual disability who do receive transplants do just as well as those with average intelligence.20,21 In the decision about whether to offer a transplant to a child, the benefits and burdens to that particular child should always been taken into account, but the intellectual disability should not, in and of itself, be a contraindication to transplant.22,23

Amelia’s parents perceived her to have been discriminated against on the basis of her intellectual disability and did what they needed to do to get her the transplant that saved her life. It is likely that many of Amelia’s earliest supporters also had her best interests in mind, and they may have particularly connected with her family because the blog was published on a platform that supports families of children with Wolf-Hirschhorn syndrome. But the broader public who “liked” or “shared” Amelia's story only knew part of the story. Privacy legislation prevented the hospital and physician involved from telling their side of the story, as is common in cases in which a patient or family brings a story to public attention. Hospital and health care workers in other high-profile cases have reported extreme distress at being at the center of a media “circus” and even receiving defamatory comments and threats of violence.24,25

In his excellent book, *So You’ve Been Publicly Shamed*, Jon Ronson observes that “with social media, we’ve created a stage for constant artificial high drama. Every day a new person emerges as a magnificent hero or a sickening villain. It’s all very sweeping, and not the way we actually are as people.”26

CHOP admitted to their communication errors with the family, but it is hard to justify the public shaming they endured as part of the story. As social media consumers, we should be careful to ensure that we do not jump to conclusions and that we attempt to get as much information as possible before jumping onto public bandwagons of either support or condemnation.
RILEY HANCEY: SMOKE AND MIRRORS

Riley Hancey was a 20-year-old outdoor enthusiast who developed severe pneumonia and was told that he would need a lung transplant to save his life. He was initially denied transplant listing at the University of Utah, according to his family, because he tested positive for tetrahydrocannabinol (THC, the active ingredient in marijuana) after smoking with friends at a party.27 After a 2-month search for a program willing to accept him, he received a transplant through the University of Pennsylvania, but within weeks, he succumbed to posttransplant complications. The University of Utah would not comment on his specific case but stated, “We do not transplant organs in patients with active alcohol, tobacco or illicit drug use or dependencies until these issues are addressed, as these substances are contraindicated for a transplant.”27

Marijuana use is a controversial area in organ transplantation, especially in pediatrics. Marijuana use is discouraged for even healthy adolescents because of its potential for addiction and long-term complications, and underage use is prohibited even in countries that have legalized the drug for adult use.28 Marijuana metabolites can affect immunosuppressant drug levels, and there is a risk of infections, such as fungal pneumonia, to transplant recipients from smoking the drug.29,30 Candidates with cannabis use disorder diagnosed after a transplant (estimated to affect ∼2.7% of the general adolescent population) do demonstrate lower graft survival in the first year post transplant.31

Some providers worry that a marijuana user will not succeed post transplant, so a restriction based on this criterion can be justified on the basis of utility. In a survey of heart and lung transplant providers, for example, only 17% endorsed listing a patient who uses marijuana for heart transplant in a state where the drug is illegal.32 But there is increasing evidence that overall graft survival is not adversely affected by recreational or medicinal marijuana use.33,34 A restriction based on drug use smacks more of stigma against users than a sound, utility-based decision, overemphasizing the deleterious effects of marijuana in a way that we would not do with other deleterious behaviors (sedentary lifestyle, unhealthy food choices, recreational alcohol use, etc).35

Riley’s family was extremely grateful that Riley did receive a transplant, stating, “Penn did everything in their power. They did everything humanly possible, and they did it with such love and professionalism. They cared from the bottom of their hearts.”36 Although the University of Pennsylvania should be lauded for offering a transplant to this patient and his family in desperate straits, we should not be so quick to condemn the University of Utah or the other sites that rejected the family. In 2017, the year that Riley received the transplant, the University of Pennsylvania performed 83 deceased-donor lung transplants, and the University of Utah performed 22. The difference in approach may have been due to different approaches and acceptance of drug users, but it may also have been due to more experience at a larger center or more buffer room to accept a riskier transplant without triggering a Centers for Medicare and Medicaid Services audit. There may be more to the story than the family’s account can reveal on its own, and lauding one transplant center and demonizing others likely oversimplifies a difficult decision. As the Association of Health Care Journalists advises, we should recognize that most stories involve altruism, love and professionalism. They cared for Riley the way they would for any other, and they did with such care, love, and professionalism. They did everything humanly possible. They did everything in their power.”27

CONCLUSIONS

Transplant policy is and will continue to be affected by the rise of social media. Families who are trying to get their children on the transplant lifeboat have more power than they had in the past; they can tell their stories to an online audience of billions and effect change for their children and others like them. Their efforts to save their children’s lives are understandable and admirable. Their stories can be a charge to reexamine the evidence that leads to our current policy decisions and become the vehicles for positive change. As transplant professionals, we can accept and adapt to these new forms of community by striving to be even more clear in our communications and realizing that what we say can be amplified and altered through the telling. As media consumers, we should be careful not to take every online story or account at face value, considering that there may be other sides to the story that we have not and will never hear. I suggest that ethical public advocacy can coexist with well-evidenced transplant allocation if and when the following 4 principles are considered:

1. Allocation should be always be decided on morally defensible criteria: If we are to draw distinctions between different people on the transplant waiting list or change the priority of some over others, these distinctions should be made on morally defensible criteria and the best available evidence. Factors such as life expectancy, quality of life improvement, and the potential to achieve time-limited benefits, such as growth, are morally defensible criteria. Cuteness, wealth, and ease of access to the media are not.

2. Allocation should be guided by evidence and experts: The opinion of the public is necessary to making transplant decisions but should not be normative. Courts will always be available to those
who feel that they have exhausted other areas of appeal, and decisions like those that affected Sarah’s case are likely to continue. Whenever possible, however, the systems that regulate allocation should be given the opportunity to reanalyze and revisit transplant allocation before courts get involved. This will require a commitment on behalf of the regulators to respond quickly and flexibly to patient appeals and of the waiting list candidates to attempt these avenues when possible. Patient partners in both research and regulation can help ensure that the patient voice is at the tables where these decisions are made.

3. Allocation changes should not advantage the poster child over other similar children: As compelling as Sarah’s, Amelia’s, and Riley’s stories are, they are just 3 of the >2000 children and adolescents who are waiting for transplants in the United States at any one time. Any changes to allocation policy, whether decided on emergency grounds, should be done in a way that advantages all similar patients, not just the child whose parents launched the public campaign.

4. Allocation campaigns should be used to advocate for changes to the root problem: Transplant ethics is only a lifeboat ethics scenario because there are not enough organs available to meet the demand. Better strategies to prevent and treat diseases that lead to end organ damage are needed. More public support for organ donation, better strategies to approach potential donors and donor families, decreasing discard rates, and embracing newer donation techniques, such as donation after cardiac death, can all help increase the supply. Responsible media coverage of individual transplant stories should always include some discussion of how the organ pool can be increased for all and should place the individual story in the broader context of the overall organ shortage.

**ABBREVIATIONS**

CHOP: Children’s Hospital of Philadelphia

OPTN: Organ Procurement and Transplantation Network

**REFERENCES**


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