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Rationing Lung Transplants — Procedural Fairness in Allocation and Appeals

Keren Ladin, Ph.D., and Douglas W. Hanto, M.D., Ph.D.

Organ transplantation requires explicit rationing and relies on public trust and altruism to sustain the organ supply. The well-publicized cases of two pediatric candidates for lung transplants have shaken the transplant community with emergency legal injunctions arguing that current lung-allocation policy is “arbitrary and capricious.” Although the resulting transplantation seemingly provided an uplifting conclusion to an emotional public debate, this precedent may open the floodgates to litigation from patients seeking to improve their chances of obtaining organs. These cases questioned the potential disadvantaging of children and the procedural fairness in lung allocation. But legal appeals exacerbate inequities and undercut public trust in the organ-transplantation system.

The controversy began when the parents of Sarah Murnaghan, a critically ill 10-year-old awaiting a lung transplant for cystic fibrosis, appealed through her physicians to the Organ Procurement and Transplantation Network (OPTN) for an exception to the policy that restricts lung-transplant candidates younger than 12 years to receiving organs from donors younger than 12. When this appeal failed, the Murnaghans appealed to the media, politicians, and finally a federal judge to grant access to the larger pool of lungs from adult donors. They argued that mistreatment of pediatric candidates for transplants would probably result in Sarah’s death. The merits of the case were never

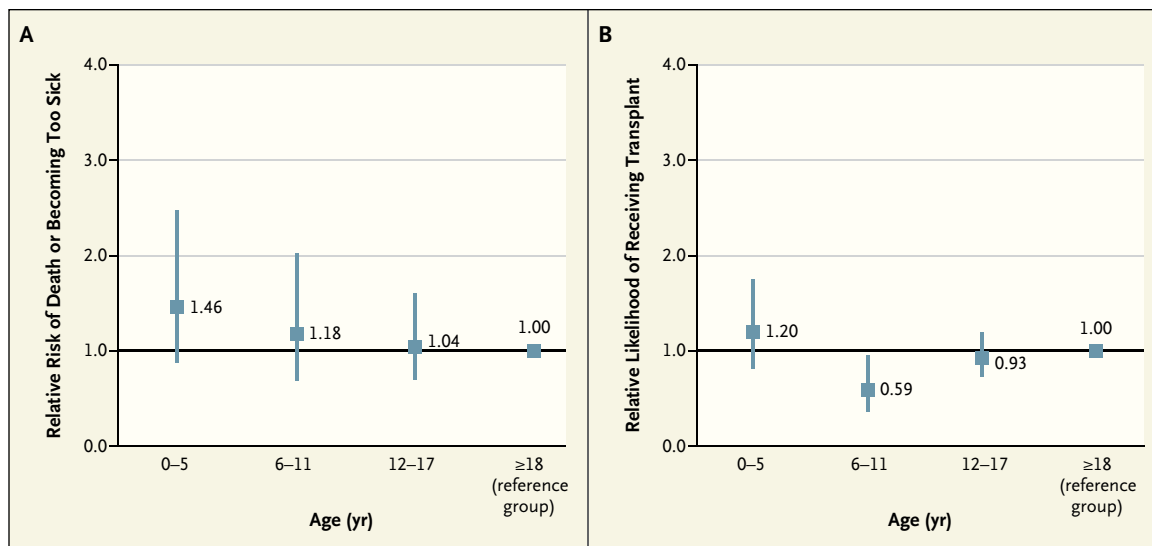
argued, since during the 10-day temporary injunction, Murnaghan received two lung transplants from adult donors. She has had serious complications, including pneumonia, and required a tracheostomy.

In 2005, to improve equity and efficiency, the OPTN switched from prioritization based on waiting time, a first-come–first-served approach that often prioritized less-urgent cases for organs, to an approach that incorporated consideration of urgency. After a 5-year review, the OPTN had developed a lung allocation score (LAS) using medical factors that predict disease severity and the likelihood of dying on the waiting list.¹ Such scores were assigned only to patients 12 or older, because there were insufficient data to support their applicability to younger populations, owing to their different diagnoses and limited outcomes data. Thus, patients younger than 12 were excluded from consideration for adolescent and adult donors’ lungs (which are allocated according to the LAS and geography) and limited to use of pediatric donors’ lungs, which are allocated according to two priority levels (different degrees of urgency based on medical criteria) and geography.

The LAS policy has increased lung-transplantation rates and reduced mortality on the waiting list among older patients.² Pediatric patients, however, continue to have higher waiting-list mortality and are less likely to receive transplants (see graphs), despite wider geographic shar-

ing of pediatric organs and the use of urgency levels — primarily because there are few pediatric donors. The supporters of the “under-12 rule” argue that it promotes equity and efficiency because of its aggregate benefits. They also cite the problematic discrepancy in lung size between adult donors and pediatric recipients. Furthermore, as a treatment for cystic fibrosis (the most common diagnosis among pediatric candidates for lung transplants), transplantation has been shown in several retrospective studies to have only marginal benefit, owing to improvements in medical management (although some data suggest otherwise).³ Lung transplantation in pediatric patients is also associated with high postoperative morbidity and mortality, largely because of the recipients’ underlying diagnoses.

Nevertheless, appeals to list children for adult organs have merit. First, designating age 12 as the cutoff arbitrarily disadvantages some children because age is a poor proxy for size. Younger patients who meet the size requirements and could benefit from adult lungs should be considered eligible. Second, in allocating other organs, we often prioritize children, partly on the basis of “fair innings” considerations (equalizing people’s chances of living until a given age) and partly because of the unique importance for physical and cognitive development that a transplant may confer. These arguments also apply to lung



Unadjusted Relative Risk of Dying While on the Waiting List or Becoming Too Sick to Receive a Lung Transplant (Panel A) and Relative Likelihood of Receiving a Lung Transplant (Panel B), According to Age Group, September 12, 2010 to March 11, 2013.

The vertical lines represent 95% confidence intervals. Ages are patients' maximum age at listing or their age at the start of the period. Data are from the Lung Allocation Policy Review from the Executive Committee of the Organ Procurement and Transplantation Network–United Network for Organ Sharing, June 10, 2013.

transplantation. Third, transplanting lungs into children is similarly efficient to doing so in adults, since their graft-survival rates are similar. Lobar resection can facilitate transplantation of adult lungs into smaller pediatric patients — also with similar results.⁴ Finally, given the scarcity of pediatric lung transplants, the data necessary for optimal validation of the LAS in this population may never be available. Without conclusive data, we should err on the side of inclusion, not exclusion from access to a broader supply of lifesaving organs. Currently, only 30 children in the United States await lung transplants, and only 11 of them are 6 to 11 years of age. The change that would occur by allowing these children access would most likely have little effect on nonpediatric candidates.

In response to objections that children are unfairly disadvantaged, the OPTN will review its lung-allocation policy during the

next year and allow expedited appeals to an expert lung-allocation board in the interim. Candidates approved during this period will gain access to the full pool of lungs on the basis of the LAS and geographic location, while maintaining their pediatric priority.

Are the organ-allocation and appeals processes fair? Despite this case, we believe they are. An ethical framework that is gaining traction in health policy, Accountability for Reasonableness (A4R), offers an approach for achieving fairness and legitimacy in allocating health resources.⁵ A4R requires transparency about the objectives of and evidence for decisions, consensus about the relevance of rationales used in resource allocation, a process for reevaluating and revising criteria in light of new evidence, and procedures for enforcing these conditions in the deliberative process. This approach claims that a fair deliberative process results in outcomes that are acceptable to all.

A4R has limitations in Murnaghan's case, including those resulting from the limited data regarding lung-transplantation outcomes in the pediatric population. But generally, organ allocation follows A4R's tenets: it is public, transparent, revisable, enforceable, and open to appeals, and it incorporates key stakeholders. Organ-allocation algorithms seek to balance equity and efficiency. Committees comprising medical and ethics experts, transplant recipients and donors, and other key stakeholders meet in a predictable and transparent way. They deliberate and issue reports and policy recommendations that are opened to public comment. Policies are enforced and revised regularly on the basis of new evidence.

Transplant candidates and their families go to great lengths to obtain lifesaving treatment. They should be assured of fair process and, in cases of error or newly available information, allowed to

appeal decisions. Appeals waged through federal courts and the court of public opinion, however, undermine fairness. Judicial appeals grant discretionary access to wealthier people, exacerbating disparities and discrimination. Moreover, appeals are inefficient, complicating allocation and leading to longer allocation times, poorer matches due to expansion of criteria, and greater difficulty in managing the waiting list. Lawsuits also inappropriately saddle courts with decisions about health policy. Finally, appeals reduce transparency and predictability, undermining the public perception of fairness, which could reduce donation rates.

Although the OPTN's allowance of appeals to an expert panel is preferable to judicial appeals, it is problematic. Relying on physicians to appeal on behalf of candidates leaves patients of lower socioeconomic status, those less informed about their options, and those lacking advocates vulnerable to worse treatment. Physicians may also fear that accepting the responsibility of mounting ap-

peals means assuming greater risk of poor outcomes and subsequent audits, which may also result in disparities.

To prevent unequal treatment, absent better data, we believe the OPTN should expand its policy to automatically assign an LAS to pediatric candidates and put those meeting the size and LAS criteria for adult and adolescent organs on the waiting list. Lung transplants should be allocated on the basis of the LAS and size match, with consideration of lobar resection for small recipients of adult lungs. Children should retain preference for lungs from pediatric donors.

Overall, we believe that the organ-allocation process is fundamentally fair, in part because of procedures in place to revise and modify allocation. It is because of this fair process that errors can be discovered and addressed. Our proposed changes would provide more lifesaving lungs to children; they would also provide useful data for the 1-year policy review and could ensure equal treatment for all

children awaiting lung transplants.

Disclosure forms provided by the authors are available with the full text of this article at NEJM.org.

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