The just distribution of organs for transplantation—the ultimate example of scarce, non-renewable, and rationed resources—is an oft-visited discussion, as it should be. The dialogue is a sobering reminder of the critical question “Who lives when not all can?” The context is of utmost importance. Approximately twenty people die each day waiting for an organ that never arrives. Recent events—well publicized by the media—have demonstrated that the distribution dilemma is not amenable to a simple “one size fits all” solution, especially when children are involved. The allocation algorithm for lungs is not the same as that for other organs. Sarah Murnaghan, a ten year old who was near death from the ravages of cystic fibrosis, ostensibly exposed an age-related ethical inequity that requires scrutiny. In this instance, Sarah’s age is critical to the discussion. Until an exception was recently introduced, lung recipients younger than age twelve were limited to lung donations from donors from the same age group. The policy was binding, at least until Sarah’s predicament, protected under the aegis of the Organ Procurement and Transplantation Network (OPTN).2

Obviously, the pool of potential lung donors for children should be expanded by moving the age of the donor pool upwards. That is exactly what Sarah’s parents petitioned the courts to sanction when all else seemed to fail and her end drew near. The judge in this instance applied an ad hoc restraining order on behalf of the Murnaghpans, and Sarah received her organ(s). Therein lies a dilemma (or a few) in contemporary pediatric transplant practice.

Why an age-based criterion in the first place? Has every attempt to gerrymander the boundaries of distributive justice based on age solely been directed at a geriatric cohort? No. There were and are age-based criteria in the realm of lung transplants affecting those patients age twelve or less. The rationale behind the age-based restriction rule is essential to an ethical discussion of what occurred in this medical dilemma that captured the national headlines.

In 2005, OPTN switched from a “first come, first served” approach for lung grafts (which had favored less critically ill patients) to an approach that considered medical urgency.3 After five years of study, a Lung Allocation Score (LAS) was derived and included medical data predicting disease severity and likelihood of dying while waiting for an organ. Benefit is a good ethical criterion to apply to the deliberations. There was a downside, however. Unfortunately, a paucity of recipients twelve years of age or less in the study meant the LAS could not be empirically applied to Sarah and other similarly aged children.4 How has the LAS model played out since?

Lung transplantation rates for older persons have increased and mortality for their demographic has likewise decreased. Conversely, however, “little children” with end stage lung disease are less likely to receive transplants, and as a result, more likely to die while waiting. Is a utilitarian calculus in effect? Overall, the “aggregate” benefit works for more people, who just happen to be older than twelve years of age. The benefits to the larger group must be weighed against the detriments to the smaller group, the patients younger than age twelve.

Before passing judgment—to be fair—there are additional confounding variables.5 Lung size is critical, that is, adult-sized lungs generally do not fit into smaller children’s thoracic spaces. So there are sound logistical reasons why adult lungs tend to go to adult recipients. Some studies also suggest that cystic fibrosis persons derive less benefit from lung transplant than persons with other diagnoses.6 Finally, there is data that suggests pediatric recipients experience a higher postoperative morbidity and mortality (less benefit) than their adult counterparts during the lung transplantation process.7

Despite attention to the efficacy/benefit criteria, from an ethical perspective Pandora’s Box overflowed in the course of Sarah’s illness and transplant. There are many things that beg consideration, some transcending age cut points. If efficacy/benefit data (pediatric outcome data suggesting children do not do as well after lung transplants as adults) is so critical to organ allocation, why are similar data ignored in other areas relevant to lung distribution? For example, more lungs would be available if double lung transplant was not the norm for adult recipients with idiopathic pulmonary fibrosis (IPF) and chronic obstructive pulmonary disease (COPD).4 There
is no compelling data that demonstrates better outcomes with double versus single grafts in these individuals—and utilization of double grafts for COPD is associated with more deaths on the waiting list (decreasing the potential impact of the lung supply for others waiting) without an increased overall life expectancy for recipients.9 Evidence-based medicine that is good for the “goose” (in this instance, potential recipients twelve years of age or less) should also be good for the “gander” (recipients older than twelve years of age with IPF or COPD).

What if a twelve year old is big for his/her age? Should he/she still be excluded based solely on age? It should come as no surprise that not all twelve year olds are the same size. But, would increasing access open the proverbial flood gates and disadvantage others? Hypothetically, if the twelve years of age or younger demographic was allowed to receive older donors’ organs in select instances, there would be little effect on organ supply. As of 2013, there were only eleven children ages 6 to 11 on lung waiting lists in the U.S.10 If they were allowed access to adult organs when appropriate, they would not deplete supply significantly. Last, but definitely not least, should a judge, after only a few days of study, overrule a committee that has had ongoing access to efficacy data for years? The judicial decision appeared to be reached in a vacuum without any expert witnesses!

Some things should be apparent already. Basing allocation on age criteria—young or old—is unjust. That said, the age-based criterion in the context of lung grafts and Sarah Murnaghan was derived from the presence or absence of critical efficacy data and not imposed solely because of her age. However, it will probably be next to impossible to derive valid LAS for twelve years of age or less. A robust number of enrollees for ongoing empiric study is simply not available. So, how should we then proceed to rectify what may be a sentinel event from the public’s perspective. This is underscored in importance all the more since transplant is totally dependent on the good will of society and must be transparent. Here are some suggestions to consider:

1. Efficacy (benefit) is a just criterion for inclusion during allocation decisions. So, the double lung allocation in present use for IPF and COPD has to be justified. If it cannot be justified, it must end. That decision alone will increase the general organ supply. While not a total solution to what is a very complex problem, I would propose it is still the right thing to do.

2. Since medical improvements make efficacy/benefit data fluid, continue to search for better data. One author favors more sophisticated modeling tools that may provide more clarity in the future.11 It may expand what we already know about lung transplants in those twelve or younger.

3. Physicians cannot wash their hands free of blame when allocation practices are questioned. If their patients are receiving double lung grafts without proven benefit, physicians must do what is right and not support that process.

4. Judges should not interfere unless a law has been broken. In this instance, the ruling appeared to be uninformed and capricious. Some have questioned whether the decision was fueled by sympathy for a child. How should appeals be handled? Since transplantation is a public trust, multidisciplinary committees with the broadest possible composition are preferable. They should have access to transparent records indicating how institutions choose recipients.

5. Efficacy data cannot remain static, especially in world of medical improvements. Children younger than age twelve with cystic fibrosis may eventually have outcome data that improves. More attention should be paid to lobar transplants in children, allowing smaller volumes of lung tissue to fit into smaller persons, growing with the recipient. Right now a paucity of data may disadvantage the little ones. If that can be changed, do it!

I am happy for Sarah Murgnahan, but unhappy with the media circus that surrounded her transplant.12 I cannot justify the judge’s actions on her behalf. The twelve-year-old rule was not ethically unsound. It may have needed tweaking (better efficacy data for this demographic and those with cystic fibrosis, a reevaluation of size optimization in larger children, and committee rather than legal responses to perceived crises), as the subsequent examination and exceptions to the policy by OPTN suggest. Double lung transplants in adults must be justified by the evidence. A single transplant, if appropriate, can serve two recipients. Sarah Murgnahan and her ordeal should teach us not to reinvent lung allocation if it is not ethically broken.

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2 Ladin and Hanto, 599.
4 Ladin and Hanto, 599.
7 Ladin and Hanto, 599.
8 Halpern, 358.
9 Ibid.
10 Ladin and Hanto, 600.
11 Halpern, 358. See for instance the overview on simulated allocation models (SAMs) as noted by the Scientific Registry of Transplant Recipients available at http://www.srt.org/sam.aspx.
12 After her first pair of lungs failed with hours of the surgery, she subsequently received a second transplant. It was reported as recently as June that she was now breathing on her own after receiving the lung transplant. Sydney Lupkin, “Sarah Murnaghan Breathing Completely On Her Own,” ABC News, June 16, 2014, http://abcnews.go.com/Health/sarah-murnaghan-breathing-completely/story?id=24161157.