Unintended consequences? - Policy changes and equity in pediatric heart transplantation

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In recent years, there has been a growing recognition of the importance of health equity. Achieving health equity, defined by the Centers for Disease Control and Prevention as the state in which everyone has a fair and just opportunity to attain their highest level of health, requires focused efforts on multiple levels, from individual behavior and attitudes to national and international policy changes. Identification of health disparities (particular types of health differences closely linked with economic, social, or environmental disadvantages that adversely affect certain groups), is the first step towards achieving health equity for a given population (1).

Racial and socioeconomic disparities have been found in outcomes for children in need of advanced cardiac therapies at all levels of care, with worse outcomes seen for minority and lower income children from presentation in heart failure, through transplant listing, and after transplant. With targeted support from PHTS, our understanding of the ways in which race, ethnicity, insurance status, and socioeconomic status affects these outcomes in children both before and after heart transplant continues to increase (2, 3).

For children living in the U.S., OPTN policy can have significant effects on outcomes both while on the waitlist and after transplant. With any change in policy, it is important to evaluate effects on health equity to ensure that benefit is seen for all children and there are no unintended worsening of outcomes or widening of health disparities. The 2016 OPTN Pediatric Heart Allocation Policy change, which aimed to reduce unacceptably high waitlist mortality for children awaiting transplant, significantly altered listing criteria and tightened the requirement for status 1A listing.

Our group used PHTS data to evaluate waitlist mortality before and after this policy change with a focus on racial disparities (4). Previous work had shown potential improvements in waitlist mortality for minority children; with this policy would these improvements continue and lead to equivalent outcomes for listed children regardless of race, or would outcomes again diverge and lead to worsening disparities? Unfortunately, we found that the latter seemed to be true. Among those listed under the old allocation system from 2012 to March 2016, white children and non-white children had very similar waitlist mortality (around 12% at 12-months), with no difference seen when controlling for other clinical factors. Under the new allocation system, waitlist mortality went down to 10% for white children while it rose slightly for non-white children to 13.4%. Risk of waitlist mortality was more than 30% higher for non-white children when controlling for other factors, including OPTN region. It was surprising that these differences were seen both in children with congenital heart disease as well as those with cardiomyopathy. We had hypothesized that we would see worse outcomes in the cardiomyopathy group due to the policy change resulting in their being downgraded to 1B. This group was more likely to be non white than in the patients with congenital heart disease. This had been a major driver of this change. The mechanisms of these widening disparities remain unclear and are likely multifactorial. How much of the change can be directly attributable to the policy change and its effects on listing criteria and how much is due to unrelated changes in care during the same period? Further understanding of contributing factors is essential for targeted interventions.

The policy change may be contributing to the unequitable waitlist outcome due to the increased use of status exceptions. Status exceptions, particularly in the period studied, are much more subjective in nature than the standard criteria. They have been shown to be unequally applied in several different organ groups. This occurs in several different factors including geographical and other patient characteristics such as race and socioeconomic status. In follow-up work using OPTN data, our group evaluated the contribution of status exceptions and their potential differential use with interesting findings. We found significant increases in status 1A exceptions amongst patients regardless of race or neighborhood socioeconomic status, but 1B exception increases were seen predominantly in high-income and non-Hispanic white children. We additionally saw worse waitlist outcomes in non-Hispanic Black children listed at lower statuses (1B or 2) compared to white children. Listing with a status exception also provided a survival advantage. It may be that status 1B exceptions, by increasing competition for donor organs in the 1B group, may be disadvantaging those listed 1B without an exception, and contributing to our failure to rescue these children before dying or becoming too ill for transplant. Clearly the decision making in these scenarios are complex, but

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more standardization in exception criteria to improve access across institutions for those who would benefit most may help improve some of these disparities. Guidelines were released in 2021 by OPTN with exactly this goal; follow-up studies will be needed to ensure that increased standardization does improve access.

As is often the case, we may be able to learn from our adult colleagues. The large number of adults needing transplant makes detecting subtle trends in relatively short periods of time a priority. This allows for rapid evaluation of policy changes that are more challenging in pediatrics and may help us gain insight into potential interventions. The OPTN adult heart allocation policy also underwent a recent change; taking place in 2018, this policy change established more status levels with more strict criteria at each level. Interestingly, despite the very different policy change, a similar effect was seen. In their recent study, Cogswell and colleagues found both measured rate of transplant and rate of delisting for death or clinical deterioration have worsened for Black waitlist candidates since the 2018 policy change (5). This remained true when controlling for co-morbidities, education and job status, as well as community-level social determinants of health. The authors note that disparities were expected to narrow with more objective criteria in the updated policy, and the fact that this was not realized may point to "the extent to which subconscious or implicit bias is embedded in clinical decision making."

It can often feel daunting to tackle these issues and push for more equitable outcomes for our patients. Many of these injustices underpinning disparities are long-standing and deep-rooted in our systems and our society in ways that can seem beyond the reach of us as healthcare providers. Any policies that we enact are subject to the society in which they are enacted. This makes it even more important for us to understand the ways in which policy changes may have unintended consequences, either by adversely affecting one population or having outsized benefits in another. The same is true for development of new medications and devices. It is imperative that we continue to collect data that will help ensure that our care delivery and outcomes are as equitable as possible for all children needing advanced cardiac therapy.

References

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