Creating a Culture of "Yes" in Pediatric Heart Donation

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Waitlist mortality for pediatric heart transplant candidates continues to remain unacceptably high, ranging from 17-30%.[1] Whereas it would be natural to assume that the solution to improving waitlist survival hinges on increasing organ donation rates, studies show that nearly 50% of pediatric hearts offered for transplantation are not utilized. Although some of these refused organs are of inferior quality and should not be used for transplantation, our understanding of what makes a donor heart "acceptable" is still evolving. An historic lack of consensus on what donor features are relevant to post-transplant outcomes coupled with entrenched institutional beliefs likely contributes to an important proportion of these hearts inappropriately refused based on "risk factors" not supported by the extant medical literature.[2,3] With an increasing number of pediatric patients being listed for heart transplantation and a relatively steady donor pool, increased utilization of appropriate donor organs remains a critical area in which we can improve waitlist outcomes.[4]

The pursuit to better understand acceptable donor heart characteristics is relatively new. In 2013, using the Pediatric Heart Transplant Study (PHTS) database, Conway et al. published the first multi-center study focused on donor characteristics and post-transplant outcomes for pediatric patients, demonstrating that donor cause of death, need for inotropes and donor cardiopulmonary resuscitation (CPR) did not affect post-transplant survival despite a traditional belief that these features defined a "marginal donor".[5] The authors note that the lack of studies guiding physicians available at that time likely contributed to the mischaracterization of appropriate donor hearts as unacceptable, concluding that parameters for accepting a donor heart could be expanded with a better understanding of donor factors.

Since then, the last decade has seen a flurry of literature aimed to shed light on the impact of specific donor characteristics traditionally believed to impact post-transplant outcomes, culminating in 2020 with an International Society for Heart & Lung Transplantation (ISHLT) consensus statement on donor acceptability in pediatric heart transplantation.[1] This paper, which aimed to "ensure that no usable donor heart is discarded, waitlist mortality is reduced, and post-transplant survival is not negatively impacted" cited nearly 40 papers published in the last decade covering a wide range of topics dispelling many long-held beliefs about donor characteristics previously believed to impact donor quality and post-transplant outcomes.[1] With so many studies characterizing both relevant and irrelevant donor features published during this time, one would expect that this shared knowledge would favorably impact donor acceptance practices with increased allocation of organs previously believed unacceptable. Although measuring this kind of change is difficult, there is little evidence to suggest that our donor acceptance practices have changed much over time. This is not surprising when one considers that what influences an individual physician's decision to accept or reject a donor offer goes beyond their knowledge of the medical literature. Decisions are influenced equally, if not principally by behavioral motivators, including fatigue when donor decisions are made the middle of the night, or regulatory incentives, including the desire to avoid societal scrutiny or medical-legal risk. Similarly, the decision to accept or reject a donor offer may be motivated by the desire to protect one's program's reputation, as donor declines are not tracked as a quality measure, but post-transplant survival statistics are available publicly. Lastly, and probably most importantly, despite our best intentions, we are personally motivated to be overly conservative when it comes to donor offers as post-transplant mortality is often internalized by providers as an individual failure whereas waitlist mortalities are more easily attributed to non-personal factors, like the inadequate donor supply, natural progression of pediatric heart disease, or a dysfunctional organ allocation system.

Yet, improving our utilization of truly appropriate donor heart offers remains difficult; barriers to learning from our collective experience abound. Firstly, the acceptance criteria employed by many centers are too strict, making it impossible to know where the boundaries of acceptable donor quality lie. This is particularly true for low-volume transplant programs whose survival statistics suffer disproportionately from individual patient mortalities, fostering more risk-averse donor acceptance practices, often to their own detriment, as this approach has been shown to result in longer wait list times and worse post-transplant survival. Secondly, donor heart acceptance practices vary greatly between centers, driven by institutional culture as much if not

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more than by evidence-based practice, preventing our community from learning through shared experience. The end-result of all of this is that, despite our desire to get as many children as possible to transplant, when it comes to donor offers, we as a transplant community have created a culture of “no”. Regardless of what we want for our patients or our fidelity to following the medical literature, ultimately, the incentives pushing one to decline a donor offer overpower those pushing one to accept. Even worse, we appear to be stuck in a cycle where our practices serve to reinforce our existing beliefs rather than encouraging us to grow.

So, how do we change? If individualism is the problem, then community is the solution, whereby working together to create a culture of “yes”. Community discussion groups, like the Advanced Cardiac Therapies Improving Outcomes Network (ACTION)-PHTS Donor Decision Forum allow for real-time sharing of ideas and collaborative learning without the delays and drawbacks of using the medical literature, an often-inefficient vehicle for change. We must also advocate for improvements in the way the United Network for Organ Sharing (UNOS) donor offer platform presents information such that relevant data is presented clearly and in context while less relevant information (like CPR duration) is de-emphasized or omitted altogether. Lastly, we must continue to push for better characterization of donor declines through more descriptive refusal codes and easier ways for centers to study the fate of organs they refused. With these, and other interventions, together we can create the culture of “yes” that will best serve our patients.

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