Ethical Advocacy for Organ Donation by Transplant Providers

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The majority of individuals who read articles in Links are well aware of the pressing need to increase organ donation. I would like to focus on pediatric heart recipients, a group with the highest waiting list mortality of solid organ transplantation in the US.\textsuperscript{1}

As transplant providers, we are expected to be strong advocates for recipients. Speaking with my transplant care provider hat on, I am concerned that active advocacy for organ donation has been muted perhaps by our caution to avoid conflicts of interests. In specific, UNOS Policy 3.4.1 updated in 2010 entitled “Avoidance of Conflicts of Interest” states that “… neither the attending physician of the decedent at death nor the physician who determines the time of the decedent’s death may participate in the operative procedure for removing or transplanting an organ from the decedent ...

Lori West and her team reported in 2001\textsuperscript{2}, the outcomes of listing infants for the next available heart independent of their blood type. By adopting this ABO-“independent” strategy, waiting times and death for infant recipients have dramatically fallen in Canada. ABO-“incompatible” listing was introduced for infants under 1 year old in the US. The blood group O recipients, who were most disadvantaged with blood group compatible listing, have benefited coming to transplant by 30 days after ABO-I listing with an overall reduction in waiting time by as much as 45% (i.e., 87 to 48 days).\textsuperscript{3} Importantly, we now have evidence that ABO-I does not adversely affected post-transplant outcomes.\textsuperscript{4} But the UNOS listing algorithm is to allocate donors independent of blood type after traditional ABO-matching and, in many centers, as a last resort. This UNOS algorithm improves allocation of unused donors but has had a much smaller effect on waiting time mortality compared with the ABO-I algorithm in Canada that allocate all hearts independent of blood type. Evidence supports advocating for expeditiously adopting a similar allocation algorithm by UNOS.

In an effort to increase donor availability, hospitals have been mandated to increase Donations after Cardiac Death (DCD). Over the past 10 years at one institution, there has been an increased proportion of donors from DCD and a decrease in donations after brain death (DBD) despite there being no changes in patient diagnoses that came to organ donation.\textsuperscript{5} This shift has been attributed to changes in clinical practice, especially in management of patients with severe brain injury. While this trend may increase the number of kidney donors, it has the potential to decrease the number of heart donors.\textsuperscript{6} In this regard, the pediatric heart transplant community must be allowed to advocate for recipient interests without raising ethical questions about such advocacy. Witness the heated debates over the ethics of DCD following publication of the first trial using DCD donors in infant heart transplantation.\textsuperscript{7-9}

The ethical considerations surrounding DCD are important to articulate. The impact of the status quo is particularly problematic for pediatric heart donation if, as outlined above, more organ donors will be going down the DCD path. There likely will be tensions resulting from a more stringent, and therefore “intrusive”, timeline to declaration driven by the reality that short warm ischemic time is critical to successful heart transplantation. As pediatric heart transplant care providers we have to be willing to advocate for an ethical pathway to DCD for heart. In contrast to the experience with adult organ donation, where inability to obtain family consent remains a significant limitation to organ donation,\textsuperscript{10} pediatric donation
is almost always a surrogate decision without advance directives yet organ donation is desired by the majority of informed
donor families. For DCD and pediatric heart transplantation, it will be important to find a path to DCD that is sensitive to
both to the immediate needs of the surrogate to say good bye and their desire to donate - analogous to how we carefully
consent for research participation presenting the “risks” (altering the final minutes) and “benefits” (organ donation).

This benefit is real. I would like to share with you excerpts of a letter that a donor’s father wrote to a recipient’s family at
the anniversaries of their daughters’ donation and heart transplantation, respectively.

“…My loss of my wife and daughter was tragic…It would mean so much to me if you could keep me updated on your daughter.
My hopes and prayers will be with her. Sincerely, A Happy Dad.”

The experience has been that, when done professionally and with compassion, pediatric organ donation is valued by both
donor and recipient families. I believe we have a continuing responsibility to ensure that every family is given the opportunity
to consider organ donation for their child. Given the limited experience to date with infant heart transplantation after DCD,
we should advocate for a cooperative effort to collect in real time the DCD experience with the equivalent of institutional
data safety monitoring boards. If brain death seems imminent, parents should be given the opportunity to wait rather than
pursue DCD per ASTS Practice Guidelines.

Should all potential status 1A infant heart recipient families be given options at time of listing of the types of “acceptable”
donor(s)? For example, ABO-matched only or ABO-“independent”, where the later could be listed to receive the next heart
donor after considerations of waiting time and distance. For example, DBD only or DCD, where the latter could be listed to
receive the next donor, DBD or DCD?

The shortage of available donor hearts continues to limit the number of children who can benefit from transplantation in
general and for our youngest potential heart recipients in particular. On the 10th anniversary of a similar initiative, this
seems to be the right time for the Standards Committee of ISHLT to partner with a subcommittee of the UNOS Pediatric
Committee to develop Best Practice Guidelines to Ethically Maximize Pediatric Organ Donation: Cardiac Considerations.

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References:

2. West LJ, Pollock-Barziv SM, Dipchand AI, et al. ABO-incompatible heart transplantation in infants. [see comments.].
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