Understanding the ethics behind incentive schemes that drive pediatric heart transplant programs nationwide

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Joseph LaRuffa

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

Advisor

Joshua Earle, Department of Engineering and Society

Introduction

Within the pediatric heart transplant space, 40% of donor hearts are being thrown away while over 20% of children die actively waiting for a suitable replacement (Denfield, 2020). The issue is not a product of low quality donor hearts as one would expect, but rather systematic issues that cause the industry to fail the children it aims to save. Some point to the lack of standardization and objectivity in the decision making process as major issues. Less discussed are the systematic incentive schemes of pediatric heart transplant programs that have shifted the industry's priorities away from its goal of saving lives. Specifically, there are competing incentive schemes of regulated pediatric heart transplant (PHTx) programs and the healthcare industry that encourage cardiologists to prioritize their respective programs' prestige, leaving high risk patients to die on the waitlist.

I will be utilizing the utilitarian framework, and therefore right and wrong rhetoric, to judge the merits of PHTx programs as they balance preserving program prestige and saving lives. Utilitarianism aims to maximize the benefits of all involved parties and therefore directly correlates with providing the best care possible for all people, a guideline that has driven the healthcare industry worldwide for decades. Misaligned efforts, however, have led PHTx programs away from this objective, yielding underutilization of donor hearts, unnecessarily high waitlist mortality rates, and other negative impacts.

This paper aims to understand the ethics behind incentive schemes that drive pediatric heart transplant programs nationwide. In order to accomplish this, I will look at how the PHTx space has transformed over the course of history and the specific adverse issues that have developed over time. Upon identifying these problems within the context of the utilitarian framework, I discuss conceptual and implementable solutions. These solutions aim to not only

improve underperforming metrics, but also realign the efforts of PHTx programs, regulatory organizations, and cardiologists with the utilitarian framework and healthcare industry as a whole.

History of Heart Transplants and the Development of DonorNet

Throughout the mid 1900s, up until the early 1970s, individual hospitals with transplant programs and organ procurement organizations in the United States managed all aspects of organ recovery and transplantation (History, 2021). During this period, the first human-to-human transplant was performed on December 3, 1967, in South Africa by Dr Christian Barnard and just three days later Adrian Kantrowitz performed this pioneering procedure on a 19-day-old neonate, recording the world's second HTx and first PHTx (pediatric heart transplant) (Schweiger, 2015). The difficulty of performing HTx during this period of time was the limited number of organs available. If an organ couldn't be transplanted near where it was recovered, there was no system to find matching candidates elsewhere and, as a result, many organs couldn't be used simply because transplant teams were not able to locate a compatible recipient in time (History, 2021). This presented a clear problem and The South-Eastern Organ Procurement Foundation (SEOPF), a regional association of donation and transplant professionals, sought to increase the efficiency of organ placement by creating a computerized database in 1977. This database included a list of candidates awaiting an organ transplant that extended beyond the once locally limited outreach hospitals and organizations had; it was called the United Network for Organ Sharing (UNOS) (History, 2021).

The monumental change UNOS provided led to a clear expansion of the industry and quickly UNOS became outdated and incapable of handling the ever increasing number of

candidates. By the early 1980s, congress began to see the reality of performing HTx and the need for broader coordination of organ allocation and data collection. As a result, the National Organ Transplant Act (NOTA) was passed, calling for an Organ Procurement and Transplantation Network (OPTN) to be created and run by a private, non-profit organization under federal contract. UNOS was awarded the initial OPTN contract in 1986 to develop the requirements for the operation of the OPTN, and has served as the OPTN ever since (History, 2021). Over the next two decades, UNOS developed multiple iterations of internet-based platforms finally landing on DonorNet, a system in which organ procurement coordinators send out offers of newly donated organs to transplant hospitals with compatible candidates, in 2006 and has since remained with this platform (History 2022).

The Current Status of Pediatric Heart Transplants

Despite the leaps and bounds UNOS has made within the organ procurement space - getting offers of newly donated organs in front of more cardiologists to review for their respective candidate - there still exists a problem within PHTx of unutilized hearts. While UNOS's DonorNet adequately organizes and distributes donor offers to cardiologists, they simply are not being accepted. There are a number of factors that contribute to poor utilization; however, this paper will target three major issues that display a clear systematic issue and yield unacceptable performance within the PHTx space worldwide. Identifying these systematic issues places the attention on the factors that dictate cardiologists performance, rather than cardiologists themselves. Cardiologists' attempts at providing chances for high risk patients is futile if the system they are an actor in actively works against their efforts. Making this distinction is a

crucial starting point towards redefining the incentives schemes that drive these programs, returning them toward a utilitarian mindset.

Systematic Issues Crippling PHTx

Regulatory and Programmatic Pressure

Heart transplant cardiologists and programs nationwide are monitored intently based on survivability thirty days and one year post transplant. The parties in questions are not, however, questioned for the number of candidate deaths that occur while they are on the waitlist. This greatly impacts the motivation that drives these programs, focusing more on having successful heart transplants rather than saving the most lives. Inherently, this places unnecessary pressure on cardiologists, who now must balance the risk to themselves and their program (Gossett, 2020). Ideally, the decision to accept an organ would focus on the straightforward question, "will this patient benefit from this organ?", but this isn't always the case. Schnier echo's the words from Gossett saying, "medical professionals are, by nature, risk averse despite our patient-centered focus," thus, physicians or cardiologists are more likely to consider whether "the likelihood of success of this transplant is sufficiently high to risk the program's outcome if we take this organ?" (Axelrod, 2013, 1).

To clarify utilization, a prospective donor heart is sent to a center to be reviewed where it is either accepted or it is refused and then sent to the next center. Thus, if all centers refuse a donor heart, it is deemed unutilized (Schweiger, 2020). While on the surface it may seem unlikely that every program would refuse a prospective heart, one of the most influential data points for cardiologists is the number of times the donor heart has been previously rejected (Godown, 2019). Falling victim to the time pressure that is associated with reviewing a donor

heart offer, cardiologists see the number of times the offer was previously rejected and say to themselves, “What did they see that I’m not?”. It is this mindset coupled with the regulatory pressure previously mentioned that yields a low utilization rate of donor hearts. Despite the regulatory pressure, the question remains as to why cardiologists are uncertain and unconfident when reviewing a donor offer. The regulatory pressure works to convince the cardiologists that are unsure of the suitability of a donor heart to reject it by default, but why are they uncertain to begin with?

Lack of Standardized Decision-Making Process

Lack of standardization is a pressing issue. Cardiologists have only thirty minutes to determine the suitability of a prospective donor heart and decide whether they want to accept or reject it as a replacement for their candidate on the waitlist. In order to make a well informed decision, they must parse through thousands of lines of unorganized and rather non intuitive data without an objective criteria or framework. The difficulty of making a confident decision when determining the suitability of a donor heart extends beyond the unproductive visualization of data. Doctor Michael McCulloch, a pediatric cardiologists from the UVA Hospital, co-wrote a paper centered around a study that focused on the proportion of cardiologists that use certain factors to drive their decision (Godown, 2019). Dr. McCulloch, who is the client for my technical project providing resources and information to drive our research, heavily relies on the echocardiogram, an ultrasound of the heart, when determining suitability. Cardiologists receive echocardiogram results in two forms: 80% receive an informative report of the results and 47% receive the heart images from the ultrasound (Godown, 2019). Despite a large majority of non-US programs not receiving one or both of these reports, only 58% of cardiologists around

the world would routinely review the images to drive their decision (Godown, 2019). While these results support the lack of standardization, they also display another key problem that infects the organ procurement industry: missing information and poor organ management.

Missing Information and Poor Organ Management

Elliott Fisher states in, *Building the path to accountable care*, "Even when providers have rich clinical data about care within their own setting, they are generally blind to the care provided elsewhere" (Fisher, 2011, 1). More often than not, cardiologists must request data that hasn't been presented or updated in a timely manner; otherwise, they are at the liberty of the information that is presented to them. Doctor Shelby White, a cardiologist within the pediatric heart transplant program at the University of Virginia Hospital, said this in relation to the amount of data that is missing when reviewing an offer:

> "But sometimes this isn't as up to date as the information that we get when we communicate with the donor site through the Buckeye[1] team…I find myself having to ask the Buckeye team a lot. You know, for example, what drips they are on and a lot of times [what Buckeye says] it's not what's documented in Unet." (White, 11/17/2022, via interview)

Information is still missing or unavailable and cardiologists, under the time constraint to review the offer, don't have enough time to get everything they may need. This problem hinders the decision making process as one of the most influential data points in making a suitability decision is the medicine that was administered to the harvest body. As said by Doctor Firezer

[1] Buckeye is a third party team that works with organ procurement facilities to give cardiologists and PHTx programs the necessary information to make an informed decision.

Haregu, among the most important factors he looks at is “how much rocket fuel has been administered”, referring to the medicine that has been given to the prospective donor heart to maintain its health status (Haregu, 11/17/2022, via interview). Despite being active cardiologists within the same PHTx program, Dr. Haregu and Dr. McCulloch illustrate two different strategies to review a donor heart offer. If a difference exists within the same program, imagine the difference in approaches that may exist between cardiologists across the world.

Regulatory organizations remain consistent with auditing programs who underperform under the current system despite the clear disconnect between PHTx programs and cardiologists worldwide. This displays a clear failure to acknowledge the larger problem: a system that actively works against cardiologists. It is nearly impossible for a cardiologist to be successful in accurately reviewing a donor heart offer consistently and, to adhere to their program and other regulatory organizations’ pressure, cardiologists default to rejecting hearts that are more than suitable for their respective candidate patient. PHTx programs focus their efforts towards adhering to the regulations of higher organizations, rather than supporting cardiologists during a difficult decision-making process. Similarly, regulatory organizations focus more on their public image than making groundbreaking strides toward saving lives within the pediatric population. Both PHTx programs and regulatory organizations fail to illustrate a utilitarian mindset.

Returning PHTx Space to a Utilitarian Mindset

The principle of utilitarianism considers both the direct and indirect consequences of our actions. It accounts for both benefits and harms of actors affected by the system, aiming to maximize the benefits of all persons rather than stemming from self-interest (Santa Clara University, 2014). The utilitarian framework, when applied to hospital systems, strives to save

the lives of many or to “maximize the benefits of all persons”. As I have shown, the PHTx system is corrupted by the self-interests of programs as a result of misaligned regulatory oversight. There is no democratic process; the cardiologists steer the ship and we are at the discretion of their judgment, so it is crucial to understand the factors that influence it and to utilize the utilitarian framework as a guideline toward future systems.

There are multiple problem areas that have been identified, including, but not limited to, a lack of standardization when reviewing donor heart offers and inconsistency with data availability. Despite these problems actively working against cardiologists in the effort to make an informed decision, regulatory organizations remain persistent with auditing transplant programs for underperforming in a failing system. Transitioning their efforts towards targeting these problem areas will not only directly improve statistics related to PHTx, but better adheres to utilitarian framework, which calls for efforts that benefit the many, not the few. Within the current system we consistently see cardiologists reject suitable hearts either as a result of missing information, poorly displayed data, or pressure from their respective organization to stay “low risk”, but while this happens candidates are dying on the waitlist. It is these candidates that we must also consider when looking at the success of the PHTx industry and they must be considered as we look to make changes moving forward.

Improving Distribution of Knowledge Worldwide

Distributing knowledge equitably to cardiologists worldwide will set the foundation for standardization in the decision-making process. Previously, we mentioned the findings from a study conducted by Doctor McCulloch, which shed light on the differing strategies implemented by cardiologists throughout the world. This study focuses on the now, but even over the last few

decades there has been a disconnect. Doctor Thomas L'Ecuyer, a cardiologist within the pediatric heart transplant program at the UVA hospital, says this about how his thought process has changed over the years:

> "And examples are, you know, people used to think if a donor got CPR, that you shouldn't accept an organ from them because that meant that their heart wasn't going to work very well. Now, I pay no attention to whether the donor had CPR. A second thing is I used to be really worried about accepting organs where the donor was needing a lot of support to make the heart work well. At the end of the day, if the heart works well it doesn't matter what it takes to make it work well. It's going to work well for the recipient. And then number three, I think, is donors often either come in with an infection, or they get an infection while they're in their terminal hospital state and I used to worry about the possibility of transmitting an infection from a donor to a recipient. And it turns out, I don't think we need to worry about that as much." (L'Ecuyer, 12/6/2022, via interview)

Dr. L'Ecuyer illustrates two points: 1) the lack of standardization has been a pressing issue for years and exists throughout the world, within PHTx programs, and even over the career of a cardiologist, 2) cardiologists are steadily learning more and more about PHTx. The latter is something I would like to focus on moving forward. While strides have been made, there still is much to learn. Due to uncertainty, cardiologists often refrain from actively sharing information about their decision-making process to their colleagues. While in successful programs within the United States this may not have a huge impact, there is an inequality of information between cardiologists throughout the world that result in poorly performing programs. In a system where each acting party isn't attempting to maximize the amount of lives saved, then how can we claim

it is adhering to a utilitarian framework. This is where I want regulatory organizations to shift their focus toward; equitably distributing PHTx information to cardiologists throughout the world. This will not only start the process of standardization, but it actively works toward benefiting the many, considering candidates in the scope of the globe rather than those within the range of the respective PHTx program.

Increasing Research Efforts within PHTx

Effectively distributing information creates equitable knowledge in cardiologists worldwide, but further research is necessary in order to reach a standardized future. This means not only focusing efforts toward equitably distributing information and knowledge, but also towards researching effective strategies to better dictate the suitability of a given donor heart offer for a particular candidate. What this looks like is actively collecting data from donor heart offers both accepted and unutilized within the DonorNet system, analyzing them against their respective success rates. Here, the goal is to maximize the success rate of PHTx, while also expanding the number of "acceptable" donor hearts. Referring back to the statement made from Dr. L'Ecuyer, cardiologists still don't know exactly what parameters are necessary to consider and which have little to no impact on a transplant procedure. Currently, this is resulting in "acceptable" donor heart offers being unutilized, yielding 40% of donor hearts to be thrown away (Denfield, 2020). Utilization rate is a necessary metric to consider when deeming a program or the PHTx industry as a whole as successful. In an ideal world, we have 100% utilization rate and a 100% success rate for PHTx procedures; however, obviously this isn't feasible, but the closer we can get to these two figures the better we are.

Adjusting Program Culture to Support Cardiologists

Improvements to programs' culture and making adjustments to the misaligned regulations that legislate these PHTx programs are short term changes that will actively move the industry towards a future that adheres to a utilitarian framework. A major problem that cripples this industry is the fear that programs and regulations instill in cardiologists if they were to fail a procedure. Cardiologists should be held accountable for the quality at which they perform their job, but there is a necessary risk that they must take in order to adequately adhere to a utilitarian framework. For example, in a scenario where a candidate patient is actively dying, it is necessary for cardiologists to take a risk and accept a less than ideal heart in order to give said patient a chance at surviving. To illustrate this point, Dr. Haregu says:

> "Yeah, so it's kind of like beggars can't be choosers. If you have a kid. It's like the seventh day that they've been on life support of the most severe form of life support, not just a ventilator, but you're using machines to pump the blood throughout their body, and to oxygenate it. This way of existing is fraught with a lot of ways in which bad things can happen, so I might take a less than ideal heart. I might take a little farther out than I might otherwise. Because I might not get another offer before something really bad happens to the patient who is waiting. So that's always in the back of your mind when you're assessing a heart."
> (Haregu, 11/17/2022, via interview)

This mindset is a perfect picture of what cardiologists need to strive for, but it can only come if the system they are working within supports them. This means they can't be scared for their own personal well being, risking losing their job or credibility, if they take a risk for a patient in need. While this decision for cardiologists will come down to

making a difficult decision, it is their respective program's and the regulatory organization's responsibilities to do everything in their power to create a space where cardiologists feel supported. This illustrates a non-legislative change that can be implemented immediately and its benefits be seen in the short term. While there will always exist an aversion to high risk candidates, mitigating the managerial pressure will begin to shift the culture and industry norm regarding these procedures. To conclude our interview, Dr. L'Ecuyer urges my team to push for change, saying, "This is an incredibly important project that is going to make it easier for people who are in a tough spot to make difficult decisions. So the most important thing is no matter how frustrated you get with the process of your project, please just keep pushing through." (L'Ecuyer, 12/6/2022, via interview). Dr. L'Ecuyer is among a number of cardiologists that see the existing problems within the current system and want to play a role in making an impactful change.

Conclusion

The PHTx space has a number of factors actively working against cardiologists from saving the most amount of lives. The largest problems within the space include a lack of standardization and objectivity in determining the suitability of a prospective donor heart, misaligned regulations from administrative organizations, and poor program culture that fails to support cardiologists through a difficult decision making process. Among other issues, these systematic problems have yielded 40% of donor hearts being thrown away while over 20% of children die actively waiting for a suitable replacement (Denfield, 2020). More unclear, these problems have demonstrated the PHTx industry's

failure to align with the mindset of the healthcare industry. Incentive schemes that drive the PHTx industry stem from the selfish motives of regulated programs, who prioritize prestige and profits rather than maximizing lives saved. This places unnecessary pressure on cardiologists to make a near impossible decision, requiring them to think of their program rather than their dying patient. In order to better align with a utilitarian framework and the healthcare industry, the PHTx space, specifically regulatory organizations, need to shift their focus away from auditing programs and cardiologists who are struggling in a failing system and, instead, actively push for three main objectives: 1) equitable distribution of information worldwide, 2) increased research efforts to improve understanding of necessary variables during the decision making process, and 3) improve program culture to better support cardiologists. With these three objectives acting as guidelines for the future of the space, we can see a brighter future where we are actively saving the most lives possible and steadily working toward 100% utilization of donor hearts and a 100% success rate of PHTx procedures.

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