

**Towards the Development of a Dashboard to Improve Pediatric Heart Transplant
Decision-Making**

**Understanding the ethics behind priority selection on the pediatric heart transplant waitlist
and the motivation behind pediatric heart transplant programs nationwide**

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By

Joseph LaRuffa

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Connor Hyldahl, Angela Wan, Olivia Kaczmarczyk, Lilleth Snavelly, Allison Miller

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.

ADVISORS

Joshua Earle, Department of Engineering and Society

Sara Riggs, Department of Engineering Systems and Environment

Introduction

Within the pediatric heart transplantation scope, 40% of donor hearts are being thrown away while over 20% of children die actively waiting for a suitable replacement (Denfield, 2020). The clear disconnect is not a product of low quality donor hearts as one would expect, but rather systematic issues that cripple the industry and fail to give dying children a fighting chance. Among the largest problems within the space is the lack of standardization and objectivity in the decision making process, but there also exists questions behind the true motivation of programs. Currently, cardiologists are required to interact with an archaic system: analyzing spreadsheets worth of data to gain a picture of the current status of the prospective heart and its ability to be a suitable match for their patient. Rather than invoking confidence in the cardiologist's decision, they are left uninformed and uncertain. My technical project aims to reduce this friction by developing a dashboard that provides comprehensive summaries of key variables; improving efficiency and reducing uncertainty in the decision making process. However, even with these changes, there are still regulatory issues at play. Specifically, there exists competing incentive schemes of regulated programs and the healthcare industry where programs benefit from allowing high risk patients to die on the waitlist. This paper will shed light on the misaligned regulations that motivate organ transplant programs, shifting their focus toward maximizing the number of lives saved rather than prestige and profits. Plato states, "Because large sailing vessels by their very nature need to be steered with a firm hand, sailors must yield to their captain's commands; no reasonable person believes that ships can be run democratically", explaining the need of an authoritarian structure due to the unique expertise and skill required to captain a ship (Winner, 1980, 129). The pediatric transplantation space is no different; we are at the will of the cardiologist to make an informed decision with good intentions, so it is crucial to understand the

inherent factors that influence their judgment. Tackling this issue from two distinct angles: technical improvements to the dashboard and regulatory restructuring will allow for a collectively exhaustive solution, where each approach will provide unique insights into the other.

Technical Project

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. As a result, nearly 20% of candidate children who have serious heart problems and are placed on the transplant waitlist die before receiving a replacement donor heart in the United States.

Furthermore, about 40% of donor hearts are unutilized (Denfield, 2020). My project aims to design a dashboard to assist cardiologists in making donor acceptance decisions in the realm of pediatric heart surgery by providing a comprehensive overview of the donor heart. We hope to display the data in an efficient and organized manner as well as incorporating metrics and indicators to help cardiologists reach a more confident decision in a timely manner. We anticipate this will naturally improve overall survival rate by increasing the number of donor hearts accepted and thus less time that candidates are on the waitlist.

The difficulty of making a confident decision when determining the suitability of a donor heart extends beyond the unproductive visualization of data. There exists a lack of standardization, which cripples the chances of a prospective donor heart from being accepted. To illustrate this point, Mike McCulloch, a cardiologist at 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). McCulloch, who also acts as the client figure for this technical project providing resources and information to drive our research, heavily relies on the echocardiogram, an ultrasound of the heart, when determining suitability. This echocardiogram can be provided to cardiologists 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 a key problem that infects the organ procurement industry. As 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. 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 Haregu, among the most important factors I look 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. While this topic falls outside of the reach of our dashboard, it does support the claim that the industry is not making appropriate efforts to save the most amount of lives as prospective organs are drastically under utilized.

Interviewing Cardiologists within the UVA program, including, but not limited to Dr. McCulloch and Dr. Haregu referenced above, has provided personalized perspectives to the benefits and hardships of the current decision making process. This information will be

synthesized to create a preliminary prototype dashboard, where the mentioned cardiologist can interact with the interface during simulated scenarios, providing key insight into certain design elements. During this iterative review stage, we will be mainly focusing on interchanging different data visualization techniques and manipulating the salience of variables to maximize efficiency of comprehension and optimize user attention. These interviews do; however, support the lack of standardization and, in the short term, our dashboard will require the flexibility and transparency to allow cardiologists to tailor their experience to meet their criteria, providing a supplementary tool to improve the existing position.

STS Research Question

To supplement the insights provided by the technical portion of this research, I would like to understand the ethics behind priority selection on the pediatric heart transplant waitlist and the motivation behind pediatric heart transplant programs nationwide. Currently, heart transplant physicians and programs nationwide are monitored intently based on the success rate of their procedures, mainly considering 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). The competing incentive schemes have yielded poor industry performance, with over 40% of prospective donor hearts being unutilized and over 20% of candidates dying on the waitlist (Denfield, 2020). To clarify the meaning of 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, in actuality the most influential data point for cardiologists is the number of times the donor heart has been previously rejected. This endless cycle is a product of the regulatory pressure previously mentioned and only shedding light on the malpractice and making efforts within the redesign of the dashboard to hide wrongfully influential points will improvements be made.

Social Groups

Up to this point, we have mentioned a large portion of the select set of people that play a role in the donor heart acceptance process. Clearly, cardiologists play a big role in the process as they are responsible for performing the comprehensive analysis of the provided data that partially drives their decision on the suitability of the donor heart. They directly interact with the system and thus will have a large priority in how this technology will be modified. As mentioned within the technical portion of this paper, their perspectives will be extracted through interviews and ideas implemented through iterative prototyping. In determining whether this group should be split up further, where the experience level of a cardiologist and candidate health were among the factors that were considered, it was decided that each cardiologist, regardless of candidate

health, should be presented with the necessary information to accurately classify the suitability of said donor heart. Moreover, certain information like the number of institutions that have previously rejected a donor heart should be withheld regardless of cardiologist experience or candidate health because a suitable heart should be accepted every single time without outside influence.

From here, it is important that we identify the private and government organizations that run and provide oversight for this process. The Organ Procurement and Transplantation Network (OPTN) and the United Network for Organ Sharing (UNOS) will both represent a different social group each with their own agenda and regulations to adhere to (Butler, 2020). OPTN provides the oversight for transplantation programs, ensuring their success rate meets benchmarks and processes follow guidelines (Butler, 2020). As changes are made to the overall process for accepting donor hearts, this will naturally influence the number of hearts accepted and transplants that are performed. This will force the OPTN to make changes to their system as we reach a new equilibrium around success rates and donor heart utilization as well as begin to rewrite the norm behind taking greater risks for dying candidates. UNOS represents the private organization that facilitates organ harvesting, registering the organ and its detailed information for prospective candidates, and the transportation to the candidates location (Butler, 2020). As the organization that controls the information that is presented to cardiologists, they are also an important social group to consider when reconstructing the system. It is important to consider the practice of recording and entering information into the system and how changes can be made to improve this process (Fisher, 2011).

Pediatric heart transplant programs that the cardiologists in question belong to must be considered as a social group for their influence in the decision making process. The motivation

behind these programs is a product of the regulations and systems created by OPTN and UNOS respectively. Their agenda places pressure on the cardiologist to perform to program standards to boost profitability and program prestige, thus resulting in a decrease in donor heart utilization (Butler, 2020). I believe there is a large amount to explore in the scope of these programs, considering poor metrics for success and culture. Despite changes that may be made to OPTN and UNOS structures, there still will be constant pressure from these programs that will continue to play a large factor.

Candidates for a prospective donor heart will not be considered as a social group, despite their large amount of influence in the decision making process. There are considerations to make information on the candidates health more salient the greater their need for a transplant; however, in any decision regarding the suitability of a donor heart the cardiologist should accept every heart they deem suitable, thus making specific candidate information more salient for some than others not necessary.

STS Framework

This research will utilize a utilitarian framework to organize the analysis and structure the argument. 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 (University, 2014). The utilitarian framework is a normative depiction of hospital systems, whose goal is to save the lives of many or to “maximize the benefits of all persons”. However, this paper has shed light on the ethical concerns around the current pediatric heart transplantation system, which has become corrupted by the self-interests of cardiologists and programs as a result of misaligned regulatory

oversight. This 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 goals. Moving forward, more detailed research will continue on the topics raised in the paper, shaping arguments within the constraints of the utilitarian framework. As further research ensues, considerations to include other frameworks to structure thoughts that fall outside of utilitarianism will be discussed as concerns arise.

Key Texts

In the efforts to build a dashboard that radically improves the existing process, there is a problem that falls outside of our reach. The article, “Building the path to accountable care”, touches on both the difficulty and the lack of accountability regarding inputting data pertaining to the care of a given patient. “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). In the context of this paper, cardiologists are often at the liberty of the information that is presented to them regarding a prospective donor heart. More often than not, cardiologists must request data that hasn’t been presented or updated in a timely manner and 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 Haregu, among the most important factors I look at is “how much rocket fuel” has been given. While this topic falls outside of the reach of our dashboard, it will get touched on in this paper by targeting the misaligned regulations and how they need to steer away from post transplant success rate and more toward overall patient survivability.

In *Pediatric Transplantation*, an official journal of the international pediatric transplantation association, a paper covering “Behavioral economics—A framework for donor organ decision-making in pediatric heart transplantation” touched on the misaligned motivation of transplantation programs. “The current transplant regulatory environment evaluates programs principally based on transplant outcomes, not waitlist outcomes. Therefore, decision-makers may make choices (eg, selectively declining organ offers) that fit the incentive scheme but not the larger organizational goals” (Butler, 2020, 1). It will be difficult to overcome these barriers within the decision making process, but they illustrate a clear regulatory problem. It is crucial that strategies are implemented to diminish the gap between the incentive scheme and larger organizational goals by creating friction in the rejection process. This is where our dashboard aims to supplement the process by improving the efficiency in which data is reviewed. The thought process is that as more data can be reviewed in an effective manner, cardiologists are able to make a more informed decision and, thus, be more confident in accepting a donor heart and placing their program at risk.

The article “Balancing accountable care with risk aversion: transplantation as a model” does a great job depicting the conflict cardiologists face when balancing the difference between their incentive scheme and the overall goals of the healthcare industry. Ideally, the decision to accept an organ would focus on the straightforward question, “will this patient benefit from this organ”? This isn’t always the case. As described by Schnier, “medical professionals are, by nature, risk averse despite our patient-centered focus” (Axelrod, 2013, 1) . As a result, 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). This argument will be utilized to back claims against the misaligned motivation of pediatric heart

transplant programs and supplement the movement to fix the existing technological systems. To elaborate, this paper supports the need for a standardized method of analyzing prospective donor hearts in order to reduce uncertainty in the decision making process and increase utilization. Moreover, this paper brings forth a dilemma with regulatory oversight where “23% of centers identified as low-performing saw an average volume of transplants performed declined by 22 cases, whereas programs with better statistics saw average volumes increase by 7.8 cases” (Axelrod, 2013, 1).

The paper, “Variability in donor selection among pediatric heart transplant providers: Results from an international survey” co-authored by my technical project client Dr. Mike McCulloch, speaks to the lack of standardization in the decision making process regarding pediatric donor hearts similar to the previous article. This article differs; however, in that its argument centers around describing the extent to which the process is unstandardized, rather than describing the implications of the problem. A survey was conducted to record the percentage of cardiologists that consider a given factor during their decision making process regarding pediatric donor heart suitability. The results support a lack of standardization, which likely stems from multiple factors including, but not limited to a lack of robust scientific evidence and the evolution of practice based on clinical experience. Individually, this information can shed light on practices where providers stand as an outlier, and those that are more widely utilized. The dashboard created within my technical project will utilize this information to aid in eliminating disparity within the industry and, in the context of this paper, this information will support a push towards removing any friction that exists in the decision making process in the hopes of rewriting the culture of pediatric donor heart programs worldwide. Moreover, it will supplement

other papers to offer insight into the psychology of the decision making process through mentions of external qualitative factors like the environment the decision was made in.

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