Designing a Dashboard to Streamline Pediatric Heart Transplant Decision Making
(Technical Paper)

Exploration of Pediatric Cardiologist Decision-Making in the United States and Canada
(STS Paper)

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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.

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Introduction

Despite high success rates in pediatric heart transplantation, 20% of children with end-stage heart failure or serious heart defects die on the waitlist before receiving a transplant in the United States (Singh et al., 2021). This is due to a combination of factors including the recipient's medical state, weight, and availability of pediatric donor organs (Dipchand, 2018). The availability of these organs decreases as the discard rate of pediatric hearts reaches almost 50% (Khan et al., 2016). This is largely because of drastic changes in waitlisted patient status, donor stability, and lack of standardized criteria for pediatric heart acceptance across programs (Singh et al., 2019). Pediatric cardiologists have less than an hour, often late in the night, to decide if they want to take a heart donation offer for a patient or wait in hopes of a better one. If they take the offer and it is not a proper match, the transplant is likely to result in patient death or heart complications for the rest of the child's life (*Heart Transplantation for Kids*, 2021b). Additionally, even though keeping a patient on the waiting list poses a greater risk to their lives, programs are incentivized to decline high-risk donor heart offers because the waitlist mortality rate is not used in scoring program performance (Butler et al., 2020). These factors make cardiologists more likely to play it safe and reject a heart offer. Once a heart is rejected the first time, however, there is a high chance of it being discarded in the future because doctors become hesitant to use an organ that other hospitals deem an improper match.

Given the gravity of the consequences of rejecting or accepting a heart, cardiologists must be able to make their decision with certainty. The complex displays of heart donor data given to cardiologists in the United States do not make it any easier to be confident about whether they should accept a heart or not. The technical side of my project will work to improve the current patient dashboard for pediatric cardiologists at the UVA Hospital using human

factors research to display patient information in a more streamlined, visually comprehensible manner. Redesigning this system will help cardiologists assess a heart with more certainty, decreasing the pediatric waitlist mortality rate and the number of heart donations that go to waste.

With the current system, nearly half of pediatric organ offers are rejected and never used in the United States (Butler et al., 2020). Canadian hospitals choose to use many of these hearts US hospitals reject and have completed successful surgeries with them (Khan et al., 2016). Although Canadian healthcare has less available space for specialized surgeries, overall findings show that there were more transplants done in Canada than in the United States across multiple diseases (Sanmartin et al., 2006; Fernandez, 2022). For my STS project, I will investigate how differences in healthcare between the United States and Canada have led to this distinction in the organ acceptance process and transplant success. Looking into how these two countries function systematically can help us see why these differences exist and how both can improve to save more lives. Though my STS research will look at both the United States and Canada while my technical project only scopes the local area, both will help to refine pediatric heart transplants and improve healthcare systems everywhere.

Designing a Dashboard to Streamline Pediatric Heart Transplant Decision Making

The current patient dashboard given to pediatric cardiologists in the UVA Hospital uses small font, little to no color, and an unclear hierarchy of information spread out between large areas of blank space. To access valuable information and files, users must scroll and parse through messy and complicated donor data to find what they need. With the short amount of time given to pediatric cardiologists to make such high-stakes decision, the patient data should be shown as intuitively as possible. Our technical project aims to design a new dashboard that will

better assist cardiologists in making donor acceptance decisions. We hope to display patient and donor information more efficiently as well as incorporate metrics and indicators to help cardiologists interpret the most important transplant factors more quickly. This improved decision-making will ideally result in a higher overall survival rate of those in need of a pediatric heart transplant and a lower rate of discarded donors. Our end deliverables will be a high-fidelity prototype of the interface and a lower-fidelity interactive dashboard with current data.

We plan to break up the project timeline into four phases: research, draft, iteration, and prototype. To become familiar with the current system, we have done group research regarding the behavioral economics around donor-organ decision-making, donor characteristics, validation models, and more. We have also interviewed UVA pediatric cardiologists to become familiar with the decision-making process they use given the current dashboard and analyze the existing models to identify areas that could be improved. Through the end of the fall semester, we will be in the draft phase, which will start with an in-person brainstorming session to drill down key metrics and potential graphs to use in the final design. From the beginning of the spring semester until April, we will be in the iteration phase. Using Figma, we will create a wireframe of the dashboard, go through user feedback to assess usability and content, modify the wireframe, and continuously iterate. The end goal of this phase is a high-fidelity wireframe. Lastly, through the end of the semester, we will create an interactive, lower-fidelity prototype based on the wireframe using Power BI or Tableau. This will give users the experience of interacting with some features of our ideal dashboard with real-time data.

The main objective of this technical project is to improve how the system presents patient information and minimize the length of the pediatric transplant waitlist, so I decided to do my STS research on how other systems have found success in decreasing pediatric waitlist mortality.

Canada specifically has proved to take offers the United States rejects and still has higher rates of successful transplants (Rutherford, 2022). I wanted to see why this difference exists and incorporate the strengths of both systems into the dashboard to make the decision-making process more effective.

Exploration of Pediatric Cardiologist Decision-Making in the United States and Canada

Less than half of available pediatric heart donations are used in the United States, presenting a major challenge for children who need heart transplants to survive (Butler et al., 2020). With waitlists increasing globally for pediatric heart transplants, researchers around the world are looking for ways to optimize the current process and save more lives. Due to Canada's proximity, many of the hearts US hospitals reject are offered to Canadian pediatric cardiologists, who have performed successful surgeries with them (Khan et al., 2016). My STS research aims to see why the pediatric heart acceptance process differs between Canada and the United States and how each healthcare system leads to these distinctions.

To understand this difference, I plan to use theories of technological politics for my STS framework. In "Do Artifacts Have Politics?" Langdon Winner looks at how society and technology interact. A social determinist argues, "What matters is not the technology itself, but the social or economic system in which it is embedded" (Winner, 1980, p. 122). This theory sees culture, politics, and economics as the moving factors that shape the consequences of the technology around us. Winner notes that this perspective has shortcomings because it suggests that technical things do not matter at all (Winner, 1980, p. 122). So, he suggests his own argument where "rather than insist that we immediately reduce everything to the interplay of social focus, the theory of technological politics suggests that we pay attention to the characteristics of technical objects and the meaning of those characteristics" (Winner, 1980,

p.123). This take allows us to not only look at the human side of things but also look more deeply into how it has translated technologically. Technology does have politics, but they are not always obvious or intentional. Often engineers have the best interests in mind when creating new technology, but the way society is structured will naturally marginalize certain groups.

With this framework, I want to understand how the United States and Canadian cultures have influenced how their pediatric transplant technology and procedure function. The current systems of both countries are not always malicious in intent but can still discriminate. Despite the US spending more on healthcare per year, the two countries have similar health statuses, and the US has far more inequality (Skala et al., 2006). Survey findings show that adults awaiting care in Canada are more likely to cite long waiting times as their primary barrier, while American counterparts are more likely to cite costs (Sanmartin et al., 2006). Major findings of kidney disease include Canadian patients being twice as likely to receive kidney transplants than Americans, and overall findings show that there were more transplants done in Canada than in the United States across all sorts of diseases (Fernandez, 2022). I plan to do further research on all of these larger health and social factors that influence the transplant procedure and dashboard in both countries using a framework of technological politics.

Research Question and Methods

To understand the systems behind why pediatric heart transplants are managed differently in the two countries, my research question is: How do differences in healthcare between the United States and Canada influence the systems that pediatric cardiologists use in each country to determine the success of a heart transplant? This question not only aims to see what allows these differences to exist but *why* they do at a systematic level. Answering this question could

help improve healthcare in both countries and create a solid standard procedure across the world to save more children's lives and prevent organ donations from going to waste.

I will gather data by communicating with pediatric heart transplant cardiologists and data scientists working for the UVA hospital and asking them questions regarding how the system currently works, how they decide when a heart should be accepted, and what features would simplify their decision-making process. I plan to conduct around 3-4 interviews with the same structure of questions. If feasible, I hope to ask UVA cardiologists if they have any connections to Canadian cardiologists and conduct similarly structured interviews virtually. Additionally, to increase the scope of information beyond UVA, I will also conduct a literature review to learn more about heart acceptance strategies and healthcare system differences that already exist in both the United States and Canada. This will include insurance and program scoring systems. Although pediatric transplantation is practiced around the world, I decided to narrow my scope to the US and Canada because they are likely to use the same pool of available hearts given their proximity. The range of these articles will include not only pediatric heart transplant information but kidney transplants and cystic fibrosis as well. I chose to broaden my scope because transplants have similar decision-making systems across organs and looking at overall transplant culture can help explain heart transplantation differences. Both methods will help increase knowledge about what aspects of the system need to change in both countries and how healthcare influences them.

Conclusion

Children listed for heart transplantation face the highest waiting list mortality in solid-organ transplantation medicine (Almond et al., 2009; Baez Hernandez et al., 2020). Though both have strengths in the pediatric cardiac field, Canada and the United States have seen a decline in

heart donor usage ratings in the past couple of years, indicating that both systems still need improvement (Dharmavaram, 2021). My STS research aims to see how healthcare differences between the United States and Canada exist. This can then help improve my technical project, where my group and I plan to create a heart transplant dashboard to streamline the organ-accepting process.

The anticipated reason for these distinctions lies in the private versus public healthcare systems in the United States and Canada, respectively. These differences may have spanned since the founding of each country. Even though it may be difficult to change deeply embedded culture even with understanding the differences, simplifying the decision process for heart transplants can help standardize procedures for other types of organ transplants and therefore benefit a larger part of the healthcare system as well. It can also change how we collect and organize data to be more comprehensible for humans and work to enhance systems beyond the transplant field.

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