Design of online dashboard for analyzing pediatric donor heart and recipient data

Development of criteria guiding pediatric donor heart selection and the potential impacts of recent innovations on such criteria

A Thesis Prospectus
In STS 4500
Presented to
The Faculty of the
School of Engineering and Applied Science
University of Virginia
In Partial Fulfillment of the Requirements for the Degree
Bachelor of Science in Systems Engineering

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December 8, 2022

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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

The field of pediatric heart transplantation is a small, but crucial, sector of the medical industry that has seen a wide range of improvements since the first surgeries were performed several decades ago (Javier et al., 2021). In 1967, the first pediatric heart transplant was conducted on a 17-day old infant by a team of specialist doctors in Brooklyn, New York (Morales et al., 2007). While the infant only survived for a short period of time following the surgery, the operation was seen as a breakthrough in medical science that represented a culmination of years of research and innovation. Since that time, advances in medications, donor procurement and preservation techniques, and post-surgery management tools have allowed patients to continue to experience many years of quality life following a surgery (Norman, 2022). The operation, which is a transplantation conducted on pediatric patients with end-stage heart failure to replace a struggling heart with a donor heart, has now become an accepted and efficient method that is performed approximately 600-700 times worldwide each year (Bock, 2022). Currently, the one and five year survival rates of pediatric heart transplants have steadily increased largely due to these new tools and techniques as well as an overall better understanding of the factors that impact post-transplant survival. However, there are still issues circulating throughout the field, including the fact that up to 44% of available donor hearts are discarded in the United States despite the number of patients on the waitlist exceeding the total number of donor hearts available (Gossett et al., 2020). This presents a major problem for both medical specialists and patients across the country, especially considering that waitlist mortality rates can reach as high as 30% at small volume centers (Denfield et al., 2020).

While there is not a single explanation for this high discard rate, recent studies have found that a combination of regulatory standards, human behavioral factors, ethical

considerations, and a lack of uniform criteria for determining whether to accept or reject a donor heart could all contribute to the underlying issue (Wright, 2021). Current practices within pediatric heart transplantation require cardiologists to review a high volume of data regarding a potential donor heart, including information on the donor organ, donor candidate, and factors such as distance to procure the organs (Dipchand et al., 2020). This leaves cardiologists with the difficult challenge of assessing the data to determine whether a potential donor heart is suitable for a patient on the waitlist, with the decision often needing to be made in a short period of time. To add to this challenge, there remains a high degree of uncertainty amongst the heart transplantation community as to which factors actually contribute to the success of a surgery due to a lack of controlled trials, small cohorts, and global issues with studying donor characteristics (Conway et al., 2020).

Given these issues present within the field of pediatric heart transplantation, my technical project will focus on developing a new interface that cardiologists can use to assist in analyzing the data on a potential donor heart. The interface will aim to improve the visibility and understandibility of the data with the ultimate goal of allowing cardiologists to have more confidence in their decision to reject or accept a donor heart. My STS research will analyze how the criteria for accepting or rejecting a donor heart was developed, and how emerging technologies may have an impact on this criteria. In combination, my technical and STS projects will allow for a better understanding of the criteria impacting decisions made by pediatric heart transplantation cardiologists and methods for improving the decision-making process.

Design of Online Dashboard for Analyzing Pediatric Donor Heart and Recipient Data

The current process used by cardiologists to make a decision on whether to accept or reject a donor heart is both complex and lacks a clear, objective approach. When a medical

patient is designated to be in need of pediatric transplant, they are placed on a list under the United Network for Organ Sharing (UNOS) database ("Heart Transplant," 2019). From there, cardiologists at designated transplant centers are responsible for assessing data on potential donor hearts and making a decision on whether to approve the donor organ for surgery on their patient. When looking at the data provided on a potential donor heart, there are many considerations and variables that a cardiologist must take into account when deciding whether to accept a donor organ or reject it in hopes of finding a better one. Recent studies have attempted to determine which variables may be the most important in the survival rate of pediatric transplants, with factors such as donor cause of death, donor-to-recipient weight ratio, and echocardiogram results being analyzed for their importance on surgery outcomes (Shweiger et al., 2020). Despite these studies, there remains no clear criteria to guide the decision-making process, and many cardiologists are forced to rely on experience and subjective analysis. In addition to these issues, donor hearts often become available for evaluation at early hours in the morning and physicians are given less than an hour to make a decision before the heart is offered to a new patient (McCulloch, 2022). The donor data presented to physicians is also very large, messy, and lacks any visualizations or assistive features, leaving the specialists scrambling to make an informed decision in a short amount of time.

The technical aspect of my project will work to alleviate these issues by developing a new dashboard that can assist cardiologists in assessing the suitability of a potential donor heart. The dashboard will be used to present the variables and heart data currently provided to cardiologists in a more effective, organized manner that reduces the time needed to understand the information. In order to gain insights on the design of the dashboard, my capstone team and I plan on reviewing data and studies on pediatric heart transplants as well as conducting interviews

with cardiologists both within and outside the UVA medical community. With the information collected from this research and interview process, my team will use online software to design and prototype a new dashboard system that implements the priorities of cardiologists and reduces the complexity of the data presented. When conducting the design of the interface, an iterative process will be used in which the team collects feedback from cardiologists on the current design and makes changes as needed.

The goal of the new dashboard system is to allow cardiologists to make a more informed, confident decision when assessing the suitability of a donor heart. By taking into account the opinions and preferences of cardiologists, the aim of the dashboard will be to provide data in a more visually appealing, assistive manner compared to what is shown in the interface currently being used. The development of the dashboard will also assist in the STS research by identifying criteria that is currently used by cardiologists in the decision-making process. The research, in turn, will be used in the design process by providing the framework for how the current decision-making process was developed.

Development of Criteria Guiding Pediatric Donor Heart Selection and the Potential Impacts of Recent Innovations on Such Criteria

The research portion of the project will focus on identifying factors and influencers that have ultimately led to the criteria used for donor assessment in today's pediatric heart transpantation field. As with many modern industries, organ transplantation has seen a wide range of medical and technological innovations that have allowed the United States to reach a milestone of 1 million transplants as of this year ("History," n.d.). Despite this significant milestone, a lack of clear guidelines and understanding of donor characteristics amongst surgeons has caused the pediatric heart transplantation rates to plateau between 500 and 600

annually over the past decade, largely due to high discard rates (McCulloch et al., 2020). An analysis of the development of the criteria commonly used by cardiologists may therefore be helpful in addressing this issue seen within the field.

In order to understand the progression of criteria used for donor assessment, a holistic research approach will be taken that addresses both the technical and human elements of the decision making process. For example, one technology that has helped to improve the success rates of pediatric heart transplants was the creation of the Left Ventricular Assist Device (LVAD), which was approved for use by the FDA in 2008 ("Stanford Health Care," 2014). The device is used as a pump that helps the left chamber of the heart pump blood to the rest of the body and has been used as therapy for patients awaiting a heart transplant. The technology has resulted in improved recepient candidacy over time and changed some of the factors considered by cardiologists when assessing suitability (McCulloch et al., 2020).

In addition to considering technological innovations, other aspects of the heart transplantation network will be analyzed. In recent years, regulatory agencies have played a key role in the decision-making process of many cardiologists due to performance measures and expectations set by oversight committees. Recent studies have found that the policies set by regulatory agencies may cause transplant programs to discard a high rate of marginal donors to avoid probation, financial costs, or possible closure if transplant success rates become too low (Butler et al., 2019). Physicians are also influenced by personal factors such as ethical considerations, risk aversion, and speculative inferences (Baez Hernandez et al., 2020). For example, many transplant programs may choose to pass up a potential donor heart if the organ has previously been rejected by several other institutions even if no evidence exists showing that

the heart is unsuitable for surgery. These factors, amongst others, have contributed to the decision-making criteria for transplants in recent years.

As part of the analysis into the criteria impacting the acceptance or rejection of a donor heart, I plan on implementing frameworks from STS into the research. Specifically, Latour's writing about the Actor-Network Theory (ANT) will be applied to the analysis, which focuses on how human and nonhuman actors interact and influence the development of larger technological systems (Latour, 1992). This framework will be used to identify the various human and non-human actors (such as cardiologists, surgeons, patients, policies, ethical standards, and the hearts themselves) that exist within the pediatric heart transplantation system and how the interactions between these components impact the assessment process. Using Latour's vision of ANT will also allow me to draw upon specific concepts used within his writing, such as translation and delegation, to assist in analyzing the existing relationships. In addition, I plan on relating this theory to the second part of my research question, which focuses on how emerging technologies may continue to reshape the criteria for pediatric decision-making. New innovations such as the Transmedics Organ Care System have recently been tested as a way to keep donor hearts alive during transportation, which could enable surgeons to travel much farther to collect transplant organs ("Heart in a Box Technology Expands Heart Transplant Window," 2021). Predictive regression analysis tools are also being developed that could take the human aspect out of decision making, with models being used as the main way to predict outcomes through the quantification of risk factors (Zafar et al., 2018). By using the ANT framework, innovations such as these can be analyzed for their impact on the pediatric transplant field and how various stakeholders may influence their usage and implementation.

Research Methods

Overall, this paper will seek to answer the question of: What factors have influenced the criteria for accepting or rejecting a donor heart in pediatric heart transplantations, and what new technologies may impact this criteria? The analysis of this question is important as modern technologies change the way that medical professionals conduct their work and make decisions that have the potential to make major impacts on the lives of their patients. By focusing first on the development of decision-making criteria for pediatric transplants in past decades, a framework can be created that explains the impacts that technology and innovations have had on the field and what considerations have been made for different stakeholders. This analysis can then be applied to the examination of emerging technologies and the influence they will potentially have on actors within the heart transplantation field.

In order to answer this question, several different methods will be utilized throughout the research process. I plan on using a literature review to collect information and insights on the development of the decision-making process for heart transplantation in recent decades. This review will begin with looking at reports detailing the history of transplantations (both for heart transplantations and other organs) and how technologies have impacted the procedure and relevant factors that are considered by cardiologists. From there, I will look at studies that have attempted to identify the criteria used by transplant doctors in their decision-making, including analyses of behavioral, ethical, and regulatory factors, as well as any educational materials used to train cardiologists in their assessment abilities. Lastly, I will compile research from news reports and scientific journals that address new technologies that are currently impacting the heart transplantation field, and what impacts these technologies may have on the decision making criteria and relevant stakeholders.

In addition to a literature review, I also plan on conducting at least 3 interviews with members of the UVA medical community. Specifically, I plan to interact with UVA's pediatric transplant specialists, which currently has a team of 17 professionals ranging from transplant surgeons to pediatric experts ("Pediatric Organ Transplant | UVA Children's," n.d.). These interviews will follow a semi-structured format in which the specialists will be asked a set of questions about their personal guidelines for making decisions regarding the assessment of a donor heart, as well as how recent technologies have impacted their day-to-day operations within the pediatric transplant field. While conducting these interviews will allow me to gain personal insights on the complexity of decision-making, it will also be important to note that the specialist team at UVA may rely on different decision-making criteria and interact with unique outside influences that are not present in the rest of the country. Therefore, analysis that is conducted using information collected from the interviews may not be completely generalizable to donor assessment in other regions of the United States.

Conclusion

In conclusion, the field of pediatric heart transplantations has progressed significantly since the first operations were conducted several decades ago. While new techniques, procedures, and technologies have led to increased survival rates, problems surrounding the decision-making process for accepting or rejecting an organ have led to almost 50% of pediatric donor hearts being discarded before use. In order to help address this issue, the technical aspect of my project will focus on designing an online interface that can be used by pediatric physicians to better comprehend data relating to a donor heart and make an informed decision on the suitability of the organ. The research portion of my project will correlate to this technical design by analyzing how the criteria currently used by cardiologists in the assessment process was

developed and how recent technological innovations may continue to change this criteria. Through this research, I expect to identify the various technological, regulatory, ethical, and behavioral factors that have impacted the criteria used for donor assessesment, as well as provide insight into new technologies that may influence this criteria. These results, in combination with my technical dashboard, can be used to provide valuable information in the pediatric heart transplantation field and can be used as a stepping stone into creating standardization in an area that currently lacks extensive research. In combination with future research, the project will aim to reduce waitlist mortality and organ discard rates, ultimately leading to better outcomes for medical patients across the country.

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