USING DATA ANALYSIS TO IMPROVE PEDIATRIC HEART TRANSPLANTATION

EFFECT OF ORGAN SHORTAGES ON PEDIATRIC ORGAN DONOR AND RECIPIENT SELECTION

A Thesis Prospectus
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Bachelor of Science in Systems Engineering

By
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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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Pediatric heart transplantation is a very complex field due to the risks and ethical implications associated with determining donors and recipients. In general, there is not a uniform definition as to what constitutes an "acceptable" heart donor (Godown et al., 2019, p. 2). Because of this uncertainty, about 45% of pediatric hearts received for donation are discarded (Godown et al., 2019, p. 2), and the children heart transplant waitlist has the highest mortality rate of all organ transplantation waitlists in the United States (Almond, 2008, p. 1). In addition, due to the underutilization and shortage of pediatric organs, other considerations unrelated to the patients' health have influence in the donor and recipient selection process. Different strategies have been implemented to try to increase organ donations (Sarnaik, 2015, p. 1), but a lack of pediatric organ donors has led to implicit biases towards certain social groups in the determination of recipients (Statter & Noritz, 2020, p. 3). The technical topic, which will focus on optimizing the donor and recipient match process, and the tightly coupled STS topic, which will focus on the effect of organ shortages within transplantation, will together address the uncertainty and ethical implications related to pediatric donors and recipients with the field of heart transplantation with the intent to inform future research within the field.

The technical project aims to optimize the pediatric heart transplantation process by determining the important health factors when selecting a suitable pediatric heart donor and recipient, and using the results to develop a scoring system that will assess the survival rate of the organ recipient. The project team, comprised of John Bullock, Megan Grieco, Ian Pederson, Wesley Roberson, and myself, is advised by Michael Porter, a professor in the Department of Engineering Systems and Environment, and Peter Alonzi, a professor in the School of Data Science. The STS topic aims to analyze the effect of pediatric organ shortages on the ethical considerations in obtaining organ donors and in selecting organ recipients.

Figure 1 outlines the timeframe of deliverables for the technical project in a Gantt chart. The majority of the data exploration and analysis for the technical project will be conducted in the fall, while the final deliverable and paper will be developed and finalized in the spring semester.

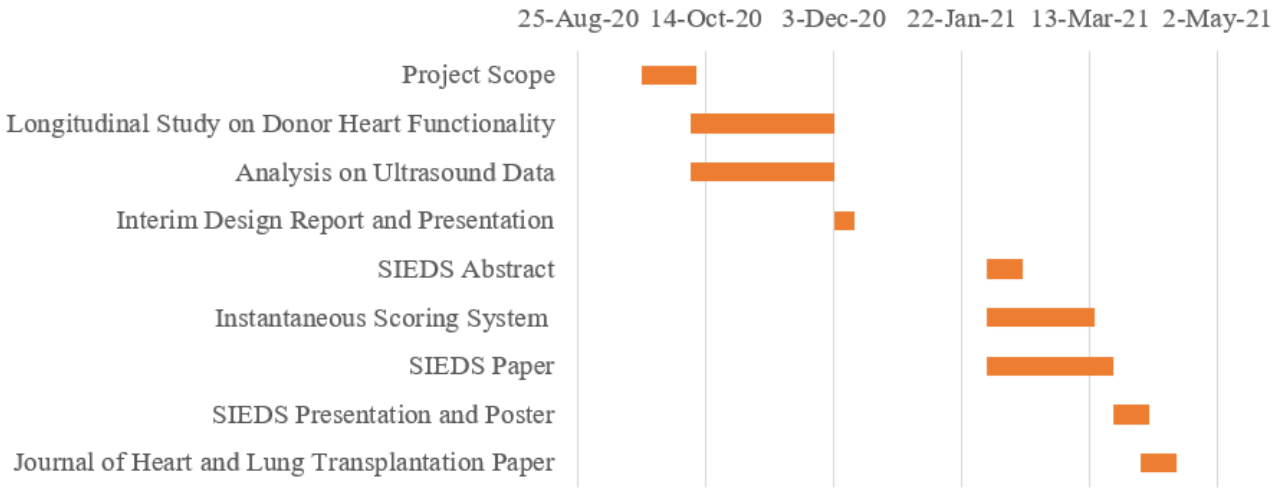

Figure 1: Technical Gantt Chart: Timeline of deliverables for the technical project and research paper (Wright, 2020).

The Gantt chart, as seen in Figure 2, outlines the timeline for the STS research paper. The preliminary research and determination of topic scope will be conducted in the fall, and the writing and completion of the paper will be done throughout the spring semester.

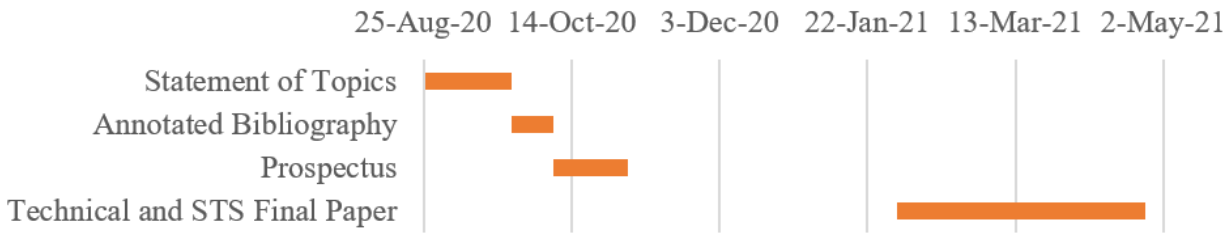

Figure 2: STS Gantt Chart: Timeline of deliverables for the STS research paper (Wright, 2020).

USING DATA ANALYSIS TO IMPROVE PEDIATRIC HEART TRANSPLANTATION

The current heart transplant process allocates donor organs through a match system, in

which prospective recipients are ranked in a list based off need and the strength of the match between donor and recipient (Organ Procurement and Transplantation Network, 2020, p. 91). Starting at the top of the list, the doctor of the recipient is notified of the donation, and has approximately an hour to determine whether they want to accept or reject the heart (Organ Procurement and Transplantation Network, 2020, p. 94). If the physician accepts the heart, the organ will be transported to the recipient for surgery; if rejected, the physician of the next highest ranked recipient is contacted to obtain the donated organ (Organ Procurement and Transplantation Network, 2020, p. 98). Figure 3 outlines a high-level view of the aforementioned steps taken during the heart transplant selection process, and indicates the specific part of the transplant process that will be addressed by the technical project.

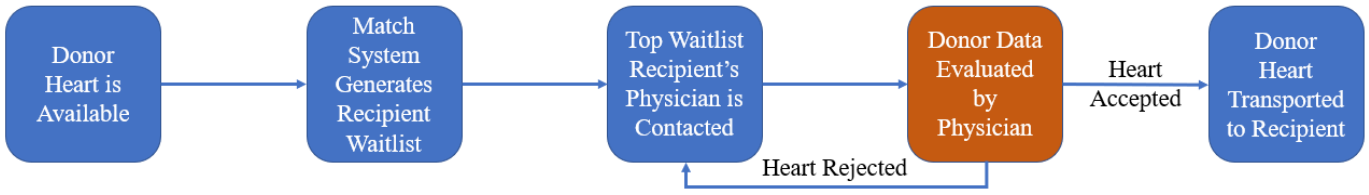

Figure 3: Heart Transplantation Process Flow: Depicts the steps of the donor heart allocation process from when a donor heart is available to when the donor heart is accepted and transported to the recipient. The orange-colored box indicates the step in the process that is to be addressed in the technical project (Wright, 2020).

While the current allocation process is well established, there is a strong underutilization of organs due to the uncertainty in evaluating donor data. While some past research has been conducted on the donor heart factors to consider when evaluating whether to accept a heart, the majority of the research focuses on adult heart transplants rather than pediatrics (Godown et al., 2019, p. 1). Specifically within the pediatric heart transplantation field, there is considerable variability between programs' usage of metrics in selecting a donor heart for a recipient (Godown et al., 2019, p. 9). A clinical study on pediatric heart patients concluded that left atrial

strains are associated with increased filling pressures in the heart, but suggest that further research be conducted into the topic to determine whether it is useful for predicting recipient survival in general within pediatrics (Loar et. al, 2019, p. 510). Since no specific heart characteristics have been determined as the best metric for assessing whether a donor heart is optimal for a specific patient, cardiac programs have to assess cases on an individual basis (Gossett et al, 2020, p. 3). In addition to metrics, a literature study conducted in 2020 by pediatric and cardiac doctors explored how various heart programs define the terms "high-risk" recipients and "marginal" donors, and their effects on organ acceptance (Gossett et al., p. 2). The study concluded that there is extreme variability in how both terms are defined, and asserts the need for a better assessment of transplant risks to help with discrepancies in evaluation (Gossett et al., 2020, p. 4).

Very little progress has been made in implementing an effective and uniform scoring system to assess the risk associated with recipient survival given a potential donor heart within pediatrics. A previous study from 2020 by pediatric and cardiac doctors evaluated currently available risk assessment models, in which only one was for pediatric patients. The model was designed to predict the mortality of the recipient one year after receiving a transplant, but was found to have weak discrimination and was not calibrated (Gossett et al., 2020, p. 4).

Due to this overall uncertainty in the decision-making process and lack of acceptable risk assessment tools, approximately 50% of donated pediatric hearts are disposed or unused, and about 20% of pediatric patients on the transplant waitlist die while waiting to receive a donor heart (McCulloch et al., 2020, p. 2). In addition to the issue of underutilization, an increasing shortage of pediatric heart donations has increased the necessity for uniformity among the

medical community as to what donor heart factors should be addressed in order to increase the number of successful transplants and recipient survival rates (Godown et al., 2019, p. 8).

The purpose of the technical project is to conduct research and analysis on past heart donor and heart recipient data in order to optimize donor heart matches and increase recipient survivals post transplantation. Pediatric donor and recipient patient data from the United Network for Organ Sharing will be analyzed to select the key characteristics of donor hearts and recipients that influence successful heart transplants with the goal of developing a longitudinal study on donor heart function and creating a scoring system that will assess the likelihood of a successful heart transplantation for a given donor and recipient. The results of the technical project will be reported in a conference paper for the Institute of Electrical and Electronics Engineers Systems and Information Engineering Design Symposium (IEEE SIEDS).

EFFECT OF ORGAN SHORTAGES ON PEDIATRIC ORGAN DONOR AND RECIPIENT SELECTION

As the demand and necessity for organ transplants increases, organ shortages have become an increasingly pressing issue within the medical field. The demand for organs heavily outweighs the supply, as over 100,000 patients needed a transplant in 2019 while less than 60% of the population were registered organ donors (Lewis et al, 2020, p. 2). Within pediatrics, there is little research on the rates of organ donation, but shortages have caused patients to have higher mortality risks and spend longer periods of time on the waitlist (Godown et. al, 2016, p. 1093).

Organ shortages have resulted in many ethical concerns, primarily related to the donor and recipient selection process. As a result of the shortage of pediatric organs, different strategies have been implemented to try to increase organ donations, such as having trained professionals speak to families about organ donations and accepting organ donations from deaths not resulting

from brain death (Sarnaik, 2015, p. 1). In addition, intervention methods prior to a donor's death have been assessed in order to maintain the strength of the organs and to increase the success of the heart transplantation. Some of these implementations have been criticized for being ethically unjust, arguing that the child's best interest is not taken into account (Brierley & Shaw, 2016, pp. 425-426). On the other hand, a lack of pediatric organ donors results in implicit bias occurring in the determination of recipients (Statter & Noritz, 2020, p. 3). For example, due to organ shortages, children with disabilities are historically not considered for organ transplants (Statter & Noritz, 2020, p. 1).

PEDIATRIC ORGAN SHORTAGES WITHIN THE ACTOR NETWORK THEORY

The STS topic will examine the limited supply of pediatric organs and the role that affiliated social groups and ethical considerations impact the overall pediatric donor and recipient selection process. The analysis will be conducted using the Actor-Network Theory (ANT) framework (Jolivet & Heiskanen, 2010, p. 6748). ANT is an approach to analyzing the interconnection of technologies, referred to as artifacts, and their interacting social groups, referred to as actors (Jolivet & Heiskanen, 2010, p. 6748.). In relation to the STS topic, organ transplants are the artifact, and the main actors influenced by organ transplants are the donor and recipient social groups. Both the donor and recipient social groups divide into three separate sub-groups: the patient, the parents or guardians, and the medical staff caring for the patient. The patients are the most directly affected by the organ transplant process as they are either giving or receiving an organ. Since the scope of the STS topic is in pediatrics, the parent or guardian plays an important role in ethical considerations related to consent and determining the best interest of the child (Brierley & Shaw, 2016, p. 426). The medical staff, specifically the surgeon, plays a crucial role in the transplant process as they administer the surgery, assess the health of the

patient, and determine whether the donated or received organ is suitable. Figure 4 provides a visual representation of the aforementioned Actor-Network Theory of organ transplants and its connected social groups.

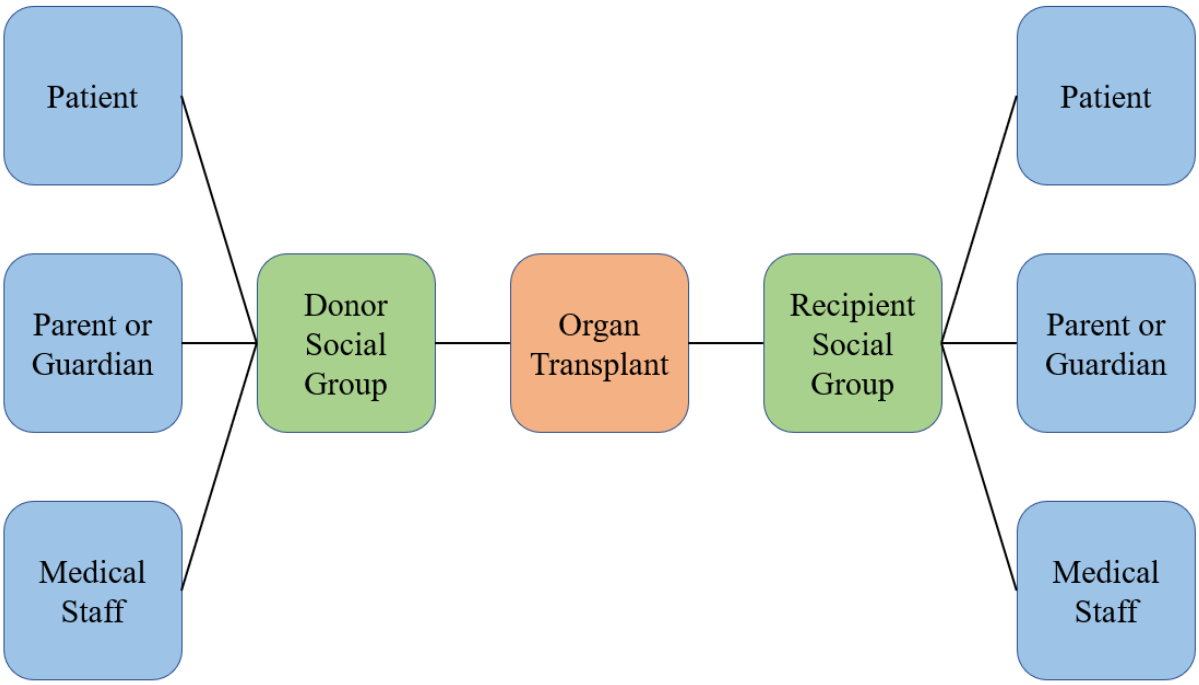

Figure 4: Organ Transplant Actor-Network Theory Diagram: The artifact, organ transplant, connects to two general social groups: donors and recipients. Each group includes the patient, parent or guardian of the patient, and the medical staff treating the patient (Wright, 2020).

By using the ANT framework, the issues impacting each social group due to the shortage can be further analyzed on an individual level within each social group. As shown below in Figure 5, the donor social groups are heavily impacted by the surge of increased efforts to raise organ donation rates within pediatrics (Lewis et. al, 2020, p.1). Some of the various strategies explored and implemented have raised many ethical concerns within the medical community related to consent and the devaluing of the donor's health in order to save the recipient (Brierley & Shaw, 2016, p 427).

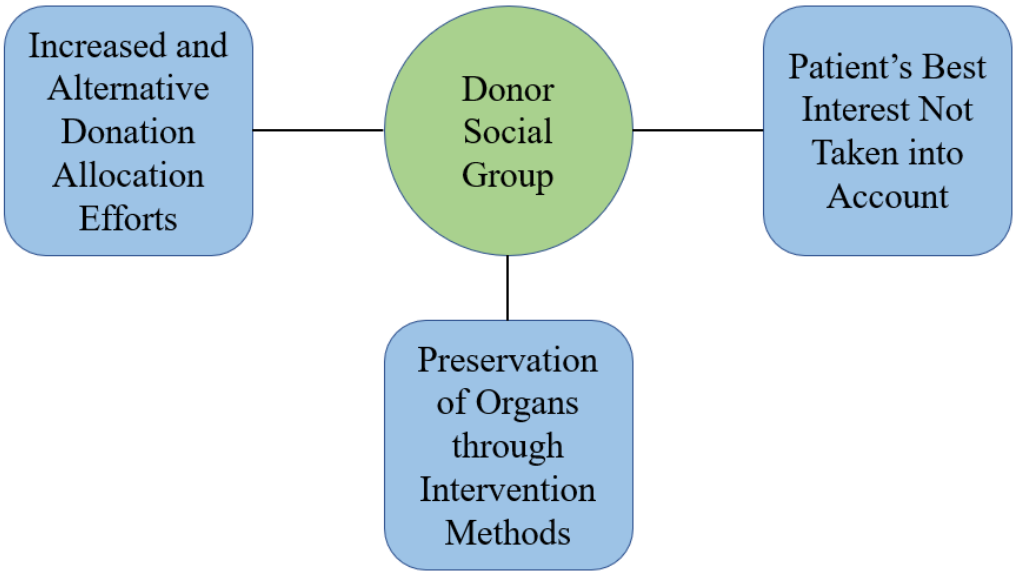

Figure 5: Organ Shortage Effect on Donor Social Groups: The lack of available organs has caused increased efforts to raise organ donation rates, the research of new technologies for organ preservation, and a lack of consideration of the child's best interest (Wright, 2020).

On the contrary, the lack of available organs has caused the organ receival process to be more selective. In some cases, marginalized groups are excluded or not considered to receive organ donations for reasons such as race (Klass, 2020, para. 18) or disability (Statter & Noritz, 2020, p. 1).

EXPECTATIONS OF STS AND TECHNICAL PAPERS

The STS research paper aims to analyze the inequitable practices within the organ transplant selection process due to organ shortages and its effects on the related social groups. In order to tightly couple this research with the technical project, research efforts will be focused specifically on pediatric organ donors and recipients, an area that currently lacks a substantial amount of research. The considerations of ethical practices in the STS research will be an important component while conducting the data analysis within the technical project. By analyzing the key heart characteristics within the context of the STS research, the overall

solution in the technical project will avoid directing biases or assumptions towards certain groups. The technical and STS paper will provide valuable information that can hopefully become the foundation for future extensive research into the topic, and will increase knowledge and provide standardization within the pediatric transplantation field.

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