DESIGNING A DASHBOARD TO STREAMLINE PEDIATRIC HEART TRANSPLANT DECISION MAKING

(Technical Paper)

THE USE AND IMPACT OF RISK INDICES IN PEDIATRIC HEART TRANSPLANT DECISION MAKING

(STS Paper)

A Thesis Prospectus Submitted to the

Faculty of the School of Engineering and Applied Science

University of Virginia • Charlottesville, Virginia

In Partial Fulfillment of the Requirements of the Degree

Bachelor of Science, School of Engineering

Lilleth Snavely

Fall, 2022

Technical Project Team Members

Connor Hyldahl

Olivia Kaczmarskyj

Joseph Laruffa

Allison Miller

Angela Wan

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

Sara Riggs, Department of Systems and Information Engineering

Joshua Earle, Associate Professor of STS, Department of Engineering and Society

INTRODUCTION

Optimally utilizing the limited organ supply in the practice of pediatric heart transplants has remained a pressing issue, especially in the United States. The graft utilization rate in the United States for pediatric hearts is rather low with only about 56% of eligible cardiac allografts ultimately being used (Khan et al., 2016, "Results" section). Unfortunately, children awaiting a heart transplant face one of the highest waitlist mortality rates in organ transplantations at about 8% in the most recent era, although this number has dramatically decreased from about 16% since the introduction of ventricular assist devices (VAD) (Zafar et al., 2015, "Results" section). Furthermore, while the supply of organs has remained steady, the number of patients being added to the waitlist continues to grow, resulting in an increasing active waitlist. The size of the active waitlist increased by over 200 patients from 2010 to 2020 (Colvin et al., 2022, Figure HR 84).

Currently, the process for evaluating a donor heart is mainly based on personal practice and institutional experience with significant inter- and intra-center practice variability. (Baez Hernandez et al., 2020, "Discussion" section). Subjectivity plays a concerningly large role in these critical decisions. Moreover, new evidence suggests that transplant survival outcomes are significantly similar for donors perceived as "high-risk" compared to "low-risk" when assessing the same recipient, suggesting the current decision making practices are suboptimal (Riggs et al., 2020, Figure 3). Time constraints, behavioral economics, and negligible factors like refusal from a previous institution may influence some of this suboptimal decision making (Butler et al., 2020). Research and studies have shown that a more comprehensive, standard, and data-driven approach to assessing the suitability of a potential donor may be beneficial for decreasing the organ discard rate and waitlist times in pediatric heart transplantations without affecting post-transplant outcomes (Baez Hernandez et al., 2020).

The protocols for evaluating other types of organs are much less subjective and variable. Tools like the Kidney Donor Risk Index (KDRI) and the Liver Donor Risk Index (LDRI) help doctors make more confident, standardized, and data-driven decisions. The kidney allocation system (KAS), which utilizes the KDRI to match patients to donor organs, has already achieved many of the policy's goals including increased fairness in allocation and improved outcomes in pediatric transplants (Stewart et al., 2016, "Discussion" section).

The technical project aims to adopt a user-centered systems design approach to develop a new dashboard to better support the decision-making process for pediatric cardiologists. The current DonorNet interface has been the primary method for pediatric cardiologists across the country to evaluate donor hearts for transplantation. The newly designed dashboard will be used to present the donor data currently provided by DonorNet in a more effective and organized manner in order to reduce the time needed to understand the information and reach a final decision regarding the acceptance or refusal of a heart. The STS portion of the thesis will explore the use and impact of risk indices in organ transplantions - looking to determine if one could be beneficial and suitable in the pediatric heart transplant field. Indices, including the KDRI and the LDRI, will be closely examined in regards to their effectiveness in increasing organ utilization and improving transplant outcomes as well as their overall adoption by the transplant community. The two projects are connected because they both investigate technologies designed to help organ transplant professionals evaluate donated organs and determine if and how they should be used. Both the technical project and the STS research focus on optimally using data to streamline and standardize donor evaluations for more confident and data-driven verdicts. The technical aspect aims to create a tool that cardiologists can leverage in decision making, whereas the STS component aims to analyze the usefulness, appropriateness, and potential consequences of quantified risk indices in pediatric heart transplant decision making.

The thesis will be completed over the course of two semesters which will include the 2022 fall semester as well as the 2023 spring semester. The technical portion of the thesis will be completed in four overarching phases: empathize, define, ideate, prototype. The empathize and define phases will be completed in the first semester, and the ideate and prototype phases will be completed in the second semester. As for the STS portion of the thesis, research, preparation and planning will begin in the first semester, and the scholarly article will be written in the second semester.

DESIGNING A DASHBOARD TO IMPROVE PEDIATRIC HEART TRANSPLANT DECISION MAKING

The technical project aims to design a dashboard that will effectively support cardiologists in evaluating donor offers for pediatric heart transplants. When a pediatric heart becomes available, cardiologists have limited time to decide whether or not they want to accept or refuse the donor organ for a specific patient – an hour if it is for the initial primary potential transplant recipient and 30 minutes for all other primary potential transplant recipients (HRSA, 2022, pg. 87). Transplant professionals often have to make these decisions in the late hours of the night based on extensive amounts of data – some of which may not even be relevant. Robust decision making practices are crucial as accepting an incompatible donor organ could result in an unsuccessful and potentially harmful transplant, while rejecting an organ means the patient must remain on the waitlist where the mortality rate remains high.

Currently, cardiologists use the DonorNet interface to evaluate donor offers and determine if the organs are suitable for use on patients within their hospitals. While the interface succeeds in displaying all relevant information, several problems exist with the current design that lead to cardiologists having a difficult time analyzing the data and coming to an informed decision. For example, all of the time-based data is presented in text format within a table rather than in graphical format making it inconvenient to visualize trends.

To create the most user-centered design, the design thinking framework will serve as a guide throughout the lifespan of the technical project. The five key steps of the design thinking framework, which will be cut down to four, are empathize, define, ideate, prototype, and test (Stevens, 2020). The first half of the project will focus on empathizing with the users and defining the functional needs of the design. Interviews will be conducted with cardiologists from multiple pediatric heart transplant programs to identify pain points with the current DonorNet system, understand the priority of variables considered when evaluating a donor, and pinpoint what information takes the most time to evaluate. In addition to the interviews, research will be conducted to understand what donor and recipient variables are significant in predicting transplant success. Traditionally, donor and recipient variables like ejection fraction, ischemic time, presence of CPR, cause of death, and use of inotropes have been used to identify "marginal" donors (Bailey et al., 2009). Moreover, non donor and recipient factors like previous rejections by other centers seem to influence decision making (Butler et al., 2020). This research, which aims to solidify which variables actually influence transplant success, will include reviewing already conducted studies, many of which run statistical analyses on the data present in the United Network for Organ Sharing (UNOS) database.

After better understanding the needs of the users, how they make decisions, and what information is truly relevant to them, the define phase will commence. Based on what is discovered in the empathize phase, a general problem statement will be specified and the functional requirements of the dashboard will be established. Together, these will serve as the foundation and guidelines for the dashboard design. The ideation phase will follow the conclusion of the define phase. This phase will consist of brainstorming innovative ways the design can fulfill the established functional needs.

After the list of insights are exhausted and the most feasible or effective design ideas are decided upon, the prototype phase will begin. This phase will consist of creating wireframes which are skeletal layouts or schematics of our dashboard, mockups which are high-fidelity but static renderings of our design, and prototypes which are early models of our design with added functionality and user flows. This process will be iterative, incorporating feedback from cardiologists who review the ongoing designs. Figma will be the main software used to design the wireframes, mockups, and prototypes. If time permits, an interactive, lower fidelity prototype based on the work done in Figma will be built using Power BI or Tableau – analytical tools that turn data into actionable information. This will give users experience interacting with certain features of the dashboard with real-time data.

The technical project will be led by Sara Riggs, a professor of the Engineering Systems and Environment department. The team members of this project – Connor Hyldahl, Olivia Kaczmarskyj, Joseph Laruffa, Allison Miller, Lilleth Snavely and Angela Wan, will work closely with Michael McCulloch, a pediatric cardiologist at UVA Children's Hospital Heart Center on the design of the dashboard. The technical project will span both the 2022 fall semester as well as the 2023 spring semester, and will result in a high-fidelity prototype of the multi-page dashboard produced via Figma.

THE USE AND IMPACT OF RISK INDICES IN ORGAN TRANSPLANT DECISION MAKING

Risk indices are used to assist doctors in quickly assessing data while making more confident, standardized, and data-driven decisions. Risk indices also help practitioners "longevity match," allowing recipient candidates with longer estimated post-transplant survival times to be prioritized when a low-risk organ becomes available (HRSA, 2020). Organ-specific risk indices are calculated by utilizing relevant donor and transplant variables to predict the risk of graft failure and to quantify graft quality. While there are currently no widely accepted risk indices for hearts, there are indices in kidney, liver, and pancreas transplantations (Akkina et al., 2012). It is important to note that these indices are calculated for all transplants, not necessarily pediatric transplants.

The KDRI includes ten donor and four transplant characteristics, each found to be significantly and independently associated with graft failure or recipient death (Rao et al., 2009). According to the Organ Procurement & Transplantation Network (OPTN), the Kidney Donor Profile Index (KDPI), a remapping of the KDRI onto a cumulative percentage scale, has been provided with all kidney donor offers since 2012 (HRSA, 2020). The LDRI includes seven donor and two transplant factors, and aims to quantify the risk associated with a specific liver donor. (Feng et al., 2006). The Pancreas Donor Risk Index (PDRI) includes 10 donor factors as well as ischemic time and predicts one-year pancreas graft survival (Axelrod et al., 2010). The creations of the KDRI, LDRI, and PDRI helped establish which variables likely influence overall transplant survival.

The intention behind these indices are to standardize, streamline, and quantify the donor evaluation process. Some believe the adoption of these risk indices will encourage the use of marginal donors to be more confidently utilized; however, critics warn against the potential for overall donor utilization to decrease through a “labeling effect” where marginal yet viable kidneys are labeled as high risk and therefore not used (Bae et al., 2016). The goal is to increase overall patient survival by decreasing the discard rate for organs that will likely result in a successful transplant.

The STS portion of the thesis will explore how risk indices like the KDRI, LDRI, and PDRI have been integrated and used in organ transplantations thus far. It will identify the consequences relative to overall transplant program success, whether those be positive or negative, incurred by their use. It will also delve into the appropriateness of risk indices in organ transplantations determined by how they align with the interests of different stakeholders. More broadly, it will consider the use and suitability of risk quantification in medicine. In her book *Risk* , Deborah Lupton discusses how risk is viewed as an objective reality “that can be measured, controlled, and managed” in science and medicine using mathematical models to quantify and predict risk (Lupton, 2013, p. 20). The STS portion of this thesis will investigate this perspective and consider the consequences of viewing risk as something that can be objectively measured. Overarching themes that will be explored include risk and risk measurement, quantitative vs. qualitative decision making, as well as objectification in healthcare and medicine.

In order to understand how risk indices are currently being used in organ transplantations and how they might be used in the future, it will be useful to draw on Actor Network-Theory (ANT) framework developed by Callon, Akrich, and Latour. ANT can provide insights on sociotechnical systems by exploring the relationships and interactions of human and non-human actors. ANT can be particularly useful in studying health information technology implementation due to the contrast between the fluid context-dependent nature of healthcare professional work and the structured, data-driven nature of technological systems. ANT has already been employed by many sociologists to examine technology implementation in healthcare settings, to explore how these technologies affect stakeholders, and to explain why information systems may be rejected by users (Cresswell, 2019). Furthermore, ANT can help uncover the conflicting interests of different stakeholders that may not allow for a single technological solution. Pertaining to the adoption of risk indices in organ transplantations, ANT will be used to understand the interests of different actor groups (donors, recipients, cardiologists, and organ procurement organizations), and how risk indices align with their interests.

This thesis section will be in the form of a scholarly article which will explore the use and impact of risk indices in organ transplantations to determine their suitability in the pediatric heart transplant field. Specifically, this section will explore how key actor groups might view risk indices within organ transplantations to determine the likelihood of adoption. Therefore, Actor-Network Theory framework will structure the research which will be conducted primarily through the literature review and document analysis research methodologies. This portion of the thesis will be conducted and formulated primarily in the Spring 2023 semester.

REFERENCES

Akkina, S. K., Asrani, S. K., Peng, Y., Stock, P., Kim, W. R., & Israni, A. K. (2012). Development of organ-specific donor risk indices. Liver transplantation : official publication of the American Association for the Study of Liver Diseases and the International Liver Transplantation Society, 18(4), 395–404. https://doi.org/10.1002/lt.23398

Axelrod, D. A., Sung, R. S., Meyer, K. H., Wolfe, R. A., & Kaufman, D. B. (2010). Systematic evaluation of pancreas allograft quality, outcomes and geographic variation in utilization. American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons, 10(4), 837–845. https://doi.org/10.1111/j.1600-6143.2009.02996.x

Bae, S., Massie, A. B., Luo, X., Anjum, S., Desai, N. M., Segev, D. L. (2016). Changes in Discard Rate After the Introduction of the Kidney Donor Profile Index (KDPI). Am J Transplant; 16: 2202–2207

Baez Hernandez, N., Kirk, R., Davies, R., Bano, M., Sutcliffe, D., Pirolli, T., Jaquiss, R., Daneman, S., & Butts, R. J. (2020). A comprehensive strategy in donor acceptance: Impact on pediatric waitlist and heart transplant outcomes. Pediatric transplantation, 24(6), e13764. https://doi.org/10.1111/petr.13764

Bailey, L. L., Razzouk, A. J., Hasaniya, N. W., & Chinnock, R. E. (2009). Pediatric transplantation using hearts refused on the basis of donor quality. The Annals of thoracic surgery, 87(6), 1902–1909. https://doi.org/10.1016/j.athoracsur.2009.03.090

Butler, A., Chapman, G., Johnson, J. N., Amodeo, A., Böhmer, J., Camino, M., Davies, R. R., Dipchand, A. I., Godown, J., Miera, O., Pérez-Blanco, A., Rosenthal, D. N., Zangwill, S., & Kirk, R. (2020). Behavioral economics-A framework for donor organ decision-making in pediatric heart transplantation. Pediatric transplantation, 24(3), e13655. https://doi.org/10.1111/petr.13655

Colvin, M., Smith, J. M., Ahn, Y., et al. (2022). OPTN/SRTR 2020 Annual Data Report: Heart. Am J Transplant. 22 (Suppl 2): 350– 437. doi:10.1111/ajt.16977

Cresswell K. (2019). Using Actor-Network Theory to Study Health Information Technology Interventions. *Studies in health technology and informatics*, *263*, 87–97. https://doi.org/10.3233/SHTI190114

Feng, S., Goodrich, N., Bragg-Gresham, J., Dykstra, D., Punch, J., DebRoy, M., Greenstein, S. and Merion, R. (2006), Characteristics Associated with Liver Graft Failure: The Concept of a Donor Risk Index. American Journal of Transplantation, 6: 783-790. https://doi.org/10.1111/j.1600-6143.2006.01242.x

HRSA. (2022). *Organ Procurement and Transplantation Network (OPTN) Policies*. OPTN.

Khan, A. M., Green, R. S., Lytrivi, I. D., & Sahulee, R. (2016). Donor predictors of allograft utilization for pediatric heart transplantation. Transplant international : official journal of the European Society for Organ Transplantation, 29(12), 1269–1275. https://doi.org/10.1111/tri.12835

Lupton, D. (2013). *Risk*. Routledge.

Rao, P. S., Schaubel, D. E., Guidinger, M. K., Andreoni, K. A., Wolfe, R. A., Merion, R. M., Port, F. K., & Sung, R. S. (2009). A comprehensive risk quantification score for deceased donor kidneys: the kidney donor risk index. Transplantation, 88(2), 231–236. https://doi.org/10.1097/TP.0b013e3181ac620b

Riggs, K. W., Kroslowitz, B. J., Chin, C., Zafar, F., & Morales, D. (2020). Pondering Higher-Risk Pediatric Heart Donors: Can We Use More?. The Annals of thoracic surgery, 110(1), 198–205. https://doi.org/10.1016/j.athoracsur.2019.09.069

Stevens, E. (2020, January 30). The design thinking process: What it is, how to use it, and what's next. Retrieved October 25, 2022, from https://www.invisionapp.com/inside-design/what-is-design-thinking/

Stewart, D. E., Kucheryavaya, A. Y., Klassen, D. K., Turgeon, N. A., Formica, R. N., Aeder, M. I. (2016). Changes in Deceased Donor Kidney Transplantation 1 Year After KAS Implementation. Am J Transplant; 16: 1834– 1847

Zafar, F., Castleberry, C., Khan, M. S., Mehta, V., Bryant, R., 3rd, Lorts, A., Wilmot, I., Jefferies, J. L., Chin, C., & Morales, D. (2015). Pediatric heart transplant waiting list mortality in the era of ventricular assist devices. The Journal of heart and lung transplantation : the official publication of the International Society for Heart Transplantation, 34(1), 82–88. https://doi.org/10.1016/j.healun.2014.09.018