Undergraduate Thesis Prospectus

Balancing Transplant Success and Waste: A Comprehensive Data Dashboard
(technical research project in Systems Engineering)

Unequal Opportunity: Transplant Denial for Disabled Patients
(sociotechnical research project)

by

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General Research Problem

How can organ transplants be made more successful?

Organ transplants are an essential, yet complicated, part of modern medicine. Transplants include a variety of organs: the kidney, liver, heart, lungs, pancreas, and intestines. The process is not straightforward for candidates, as doctors first must refer them to a waitlist prioritized by illness severity and duration on the list (UNOS, n.d.). When made available, donor organs are presented to doctors with candidates that have the highest medical urgency, while also matching factors such as distance, blood type, and size of the organ. A doctor then must decide if the donor organ is truly fit for the candidate based on a multitude of other factors.

Within transplant decision-making for doctors, there is a disparity in waitlist referrals and outcomes for patients with end-stage organ disease. Studies suggest racial transplant referral disparity, as non-white children have delayed waitlist referral times for liver transplantation in comparison to white children (Thammana et al., 2013). Further statistical analysis via machine learning modeling shows worse post-transplant outcomes for non-white recipients (Wadhwani et al., 2019), which likely results from delayed waitlist referral. Programs have also excluded patients with intellectual disabilities from transplant referrals based on their disability alone (Wightman et al., 2018). Risks reside in multiple points of the decision process, from doctors' comparison of donor and candidate organs to their decisions on patient waitlist referral.

Balancing Transplant Success and Waste: A Comprehensive Data Dashboard

How can the decision-making process of pediatric heart transplants be facilitated for cardiologists?

This capstone project is led by Sara Riggs in the Systems Engineering department as a part of SYS 4053/4054. The project collaborators are Allison Miller, Angela Wan, Connor Hyldahl, Joseph Laruffa, and Lilleth Snavely. Our client is Dr. McCulloch, a pediatric cardiologist at UVA Children's hospital.

Over 40% of donor hearts in the US are discarded (Dani et al., 2021), despite high waitlist mortality of pediatric heart candidates. Through discussions with Dr. McCulloch, we found that cardiologists often have a mere hour to determine the suitability of a prospective donor heart and then decide whether to accept it for surgery on a waitlisted patient in their institution. Currently, they must parse through pages of unorganized and rather nonintuitive data without a structured procedure to learn about the donor's heart.

We aim to design a dashboard to assist cardiologists in making donor acceptance decisions in the realm of pediatric heart surgery. We will efficiently display the data in an organized manner by incorporating metrics and indicators to help cardiologists quickly reach a more confident decision. Another desired result is a higher overall survival rate of those on the pediatric heart transplant waitlist and a lower rate of discarded donors. We are constrained to a dashboard, as this is our client's request.

The current matching process starts with a heart being donated. The United Network for Organ Sharing, a centralized hub for all transplant data, generates a ranked list of candidates who match distance and biological compatibility. The transplant program with the candidate at the top of the list is contacted and given up to one hour to decide whether to keep it based on the medical records of the donor and candidate (UNOS, n.d.). This data is presented to the cardiologist in a tabular format with no visualizations. The heart is offered to the next candidate on the list the program rejects it, which occurs when the risk is too high or it isn't a good match.

Our end deliverables are a detailed wireframe and an interactive dashboard prototype with easily digestible visualizations of the available metrics. Before dashboard design, we will conduct interviews with cardiologists to gather an understanding of the decision-making process; specifically, how they prioritize different factors when looking at donor hearts. Using this information, we'll determine which metrics to make most salient to expedite the data review process. We will use Figma, an interface design software, to map out our high-fidelity wireframe of the dashboard. The prototype, either created on Tableau or Power BI, will be less detailed, but will be interactive and inclusive of current data. Our dashboard will ultimately help cardiologists to make efficient, informed decisions on whether to accept a donor heart for their candidate patients.

Unequal Opportunity: Transplant Denial for Disabled Patients

How have disability advocacy groups pushed for equal consideration of organ transplants?

Patients with disabilities in need of organ transplants are frequently passed over as potential recipients despite the Americans with Disabilities Act prohibiting disability-based discrimination. Post-transplant outcomes are the primary concern when doctors consider transplant referral for disabled individuals. Advocacies have addressed this disparity through public exposure, education, and policy recommendations. However, there is still no widely accepted rule for doctors on disabilities as a factor in organ transplants.

Despite a national organ discard rate of roughly 13 percent (Israni et al., 2020), some doctors have withheld available organs from such patients, doubting that they can maintain post-transplant regimens. There is no universal guideline on how to consider intellectual disability in transplant decision-making, thus it varies across programs. A survey conducted showed that 24

percent of organ transplant programs consider severe intellectual disability as a contraindication when assessing waitlist referral (Wall et al., 2020). Another study found that 43 percent of programs consider intellectual disability in the listing process, but not explicitly with a negative connotation (Richards et al., 2009). However, there is no statistical difference between patients with Down syndrome and other patients in post-transplant outcomes following pediatric heart transplants. Because intellectual disabilities are irrelevant to such outcomes, they should not be a factor in transplant decision-making (Godown et al., 2022). Since people with intellectual disabilities typically have shorter lifespans, doctors' assumptions about disabled patients' life expectancy may also affect transplant decisions. Following transplants, however, short-term and long-term survival rates among patients with and without disabilities are similar (Ross, 2021).

Patient advocacies strive to reduce such transplant discrimination through publicity campaigns and direct policy recommendations. Nonprofit advocacies such as the Autistic Self Advocacy Network bring awareness to inequality in disability rights through public education. While their focus is broad, they have informative resources on transplant inequality for many groups, including recipients and clinicians (ASAN, 2013). They educate doctors primarily by providing facts on how disabled patients have the same post-transplant outcomes as non-disabled patients, as well as emphasizing the importance of a disabled person's support network. The Organ Procurement and Transplantation Network, led by doctors in transplant fields, publicly states that it's "unacceptable to use variations in transplant outcomes among social groups as a basis for predicting individual outcomes" even if a particular group has lower survival rates (OPTN, 2015). Though this public group of doctors discourages discrimination of any kind, they still have not enforced a universal rule against it. The National Council on Disability, a federal agency, promotes non-discriminatory transplant processes through policy recommendations at all

levels of government (Romano, 2019). The council also provides analysis of the effectiveness of the existing ADA regulations regarding transplants. While the ADA prohibits discrimination, it's unlikely to be enforced due to the urgency of transplants, so the council encourages litigation at the federal level to explicitly prohibit transplant discrimination, following examples of states with existing policies.

Disabled individuals who are potential transplant recipients are perhaps the most relevant participant group, as they are the ones directly affected. Charlotte Woodward is a woman with down syndrome who was able to receive a heart transplant, and has dedicated her time since to advocate for others in similar situations through a mix of spreading awareness and lobbying for non-discriminatory legislature (Norlian, 2021). Sponsored by Senator Rubio, the Charlotte Woodward Organ Transplant Discrimination Prevention Act was introduced to the Senate in December 2021. It prohibits doctors from denying transplants to individuals based on intellectual disability alone (Woodward Act, 2021). While the bill has yet to become law, it proves that the social action taken by advocates such as Woodward is effective on a larger scale. For children who cannot yet speak for themselves, family members must advocate on their behalf. Chrissy Rivera, a mother of a young girl with an intellectual disability, made a significant impact in her emotional blog post, "Brick Walls," by bringing to light the discrimination her daughter faced at the Children's Hospital of Philadelphia (CHOP). The doctor denied her daughter a kidney transplant, saying "she is not eligible because of her quality of life because of her mental delays" despite Rivera's offer to donate her own kidney (Rivera, 2012). He proceeds to explicitly say that he does "not recommend [the child] for a transplant because she is mentally retarded" and for no other medical reason. This was met with public outcry and attention from multiple media outlets, drawing criticism to CHOP. Shortly after, CHOP released a statement that they are

"completely committed to the careful review of [their] processes" concerning disabilities

(Children's Hospital of Philadelphia, 2012). The negative media attention from her story with the

blunt words of the doctor forced the hospital to review their transplant procedures.

Despite lack of sound statistical evidence for excluding patients with disabilities from

organ transplantation, groups must still fight for equal consideration by bringing awareness to the

issue. From criticizing individual programs to involving formerly uninvolved politicians, public

attention draws support to those affected and encourages policy change to ban transplant

discrimination. Programs are forced to reevaluate approaches regarding disabled patients needing

transplants when met with scrutiny. While measures still must be taken to reach true equality in

transplant consideration, advocates for disability rights have made substantial progress.

References

ASAN (2013, March). Autistic Self Advocacy Network. Organ transplants for people with disabilities: A Guide for Clinicians. https://autisticadvocacy.org/wp-content/uploads/2014/03/OrganTransplantationClinicianGuide_final.pdf

Children's Hospital of Philadelphia. (2012, February 15). Joint Statement of the Rivera Family and The Children's Hospital of Philadelphia. [Status Update]. Facebook. https://www.facebook.com/ChildrensHospitalofPhiladelphia/posts/pfbid02xaowwynZAM4GSnRLco5xfvRhBUXyoDzG1x8KF44sx6bmQcuB3rtr6PokK9WtyM3Dl

Dani, A., Heidel, J. S., Qiu, T., Zhang, Y., Ni, Y., Hossain, M. M., Chin, C., Morales, D. L. S., Huang, B., & Zafar, F. (2021). External validation and comparison of risk score models in pediatric heart transplants. *Pediatric Transplantation*, 26(3).

Godown, J., Fountain, D., Bansal, N., Ameduri, R., Anderson, S., Beasley, G., Burstein, D., Knecht, K., Molina, K., Pye, S., Richmond, M., Spinner, J. A., Watanabe, K., West, S., Reinhardt, Z., Scheel, J., Urschel, S., Villa, C., & Hollander, S. A. (2022). Heart Transplantation in Children With Down Syndrome. *Journal of the American Heart Association*, 11(10). National Library of Medicine.

Israni, A. K., Zaun, D., Hadley, N., Rosendale, J. D., Schaffhausen, C., McKinney, W., Snyder, J. J., & Kasiske, B. L. (2020). OPTN/SRTR 2018 Annual Data Report: Deceased Organ Donation. *American Journal of Transplantation*, 20(s1), 509–541.

Norlian, A. (2021, January 4). A Woman With Down Syndrome Has Fought For Organ Transplant Anti-Discrimination Legislation For Years; Now, It's Been Proposed, And Named After Her. *Forbes*. https://www.forbes.com/sites/allisonnorlian/2021/01/04/a-woman-with-down-syndrome-has-fought-for-organ-transplant-anti-discrimination-legislation-for-years-now-its-been-proposed-and-named-after-her/?sh=5aa338797841

OPTN. (2015, June). Organ Procurement & Transplant Network. Ethical Principles in the Allocation of Human Organs. https://optn.transplant.hrsa.gov/professionals/by-topic/ethical-considerations/ethical-principles-in-the-allocation-of-human-organs/

Richards, C. T., Crawley, L. M., & Magnus, D. (2009). Use of neurodevelopmental delay in pediatric solid organ transplant listing decisions: Inconsistencies in standards across major pediatric transplant centers. *Pediatric Transplantation*, 13(7), 843–850.

Rivera, C. (2012, January 12). Brick Walls. Wolfhirschhorn.org. http://wolfhirschhorn.org/2012/01/amelia/brick-walls/

Romano, N. (2019, September 25). Organ Transplant Discrimination Against People with Disabilities. *National Council on Disability*. https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf

Ross, L. F. (2021). Ethics of Organ Transplantation in Persons with Intellectual Disability. *The Journal of Pediatrics*, 235, 6–9. ScienceDirect.

Thammana, R. V., Knechtle, S. J., Romero, R., Heffron, T. G., Daniels, C. T., & Patzer, R. E. (2013). Racial and socioeconomic disparities in pediatric and young adult liver transplant outcomes. *Liver Transplantation*, 20(1), 100–115.

UNOS. (n.d.). United Network for Organ Sharing. Frequently Asked Questions. https://unos.org/transplant/frequently-asked-questions/

Wadhwani, S. I., Hsu, E. K., Shaffer, M. L., Anand, R., Ng, V. L., & Bucuvalas, J. C. (2019). Predicting ideal outcome after pediatric liver transplantation: An exploratory study using machine learning analyses to leverage Studies of Pediatric Liver Transplantation Data. *Pediatric Transplantation*, 23(7).

Wall, A., Lee, G. H., Maldonado, J., & Magnus, D. (2020). Genetic disease and intellectual disability as contraindications to transplant listing in the United States: A survey of heart, kidney, liver, and lung transplant programs. *Pediatric Transplantation*, 24(7).

Wightman, A., Goldberg, A., & Diekema, D. (2018). Fairness, severe intellectual disability, and the special case of transplantation. *Pediatric Transplantation*, *22*(5), e13228.

Woodward Act (2021). Charlotte Woodward Organ Transplant Discrimination Prevention Act, no. S.3301.