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

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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

Heart transplantation can save the life of a child with end-stage heart failure or heart defects from birth that have not improved with medication or other surgeries (*Heart Transplant*, 2022). Despite high success rates in pediatric heart transplantation, 20% of children on the waitlist die 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). Optimally using the limited organs available remains a pressing issue in the United States as almost 50% of donor hearts are discarded and never utilized for transplants (Khan et al., 2016).

Making the decision to accept or reject donor organs are pediatric cardiologists, who are doctors that diagnose and treat heart conditions in children. The number of transplants they oversee varies depending on the size and location of their program, but the gravity of each decision is no different; 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). Cardiologists have limited time to parse through a deluge of complex data, often late in the night, to decide if they want to take a donor offer for a patient or wait in hopes of a better one. These suboptimal decision-making conditions have resulted in significant variations in donor acceptance practices between and within pediatric heart transplant programs. To date, there is no consensus on what makes a donor "acceptable" versus "unacceptable" (Godown et al., 2019).

During the initial briefing of my Capstone project, I learned that even after being labeled unsafe by multiple programs in the United States, many hearts are sent to Canada and used in transplants successfully. Due to the lack of standardized criteria for pediatric heart acceptance

across programs, I was curious as to why Canadian transplant programs decided hearts that the United States had rejected so many times were safe for use. Because Canada's organ usage leads to higher waitlist survival and decreases the number of hearts that go to waste, I decided to investigate the two countries' health systems to see why differences in decision-making procedures exist and ideally improve both in the future.

My literature review covers the decision-making strategies that already exist, as well as the differences in healthcare systems and heart acceptance strategies between the United States and Canada. Further research was gathered by conducting interviews with pediatric cardiologists in the local area, across the country, and in Canada as well. These findings will be used along with the literature review to compare and see why systemic differences emerged. Ultimately, I conclude that the differences in the pediatric heart transplantation decision-making processes exist due to the distinctions in how public and private healthcare systems function and preexisting health politics between the two countries.

Literature Review

Currently, there is no standard approach to accepting heart donations due to large variability both between and within transplant centers. Though there have been attempts to standardize this process in some capacity, there are many factors that have made it difficult (Dani et al., 2021). For example, the donor-recipient body weight ratio determines acceptable donor weights for recipients, but the ideal ratio varies across programs, making it difficult for centers to agree on which hearts are safe. Differing program incentives also lead to variation; even though keeping a patient on the waiting list poses a greater risk to patients, programs are more likely to decline high-risk donor heart offers because the waitlist mortality rate is not used in scoring program performance (Butler et al., 2020). Because the current system also evaluates outcomes

rather than process, transplant mortality looks like poor decision-making even though all transplants are inherently risky. The way information is presented also plays a large role; if data indicates that other hospitals have declined an offer, following offers are less likely to be taken. This is a phenomenon called information cascading, which has led to many hearts going unused because cardiologists are hesitant to use organs other programs have deemed unsafe (Butler et al., 2020).

Differences in the organ acceptance processes exist in other transplant fields as well. Risk indices have helped doctors to assess large amounts of data and make more confident and systematic decisions for different organ transplants. While there are currently no widely accepted risk indices for hearts and lungs, there are established risk indices used for kidney, liver, and pancreas transplantations (Akkina et al., 2012). The use of risk indices may not be efficient for pediatric heart transplants because there is a lack of consensus and statistical evidence on what factors affect transplant success rates. Both data scientists and doctors familiar with the field cannot concretely agree on risk-predicting factors. Between countries, major findings of kidney disease treatment include Canadian patients being twice as likely to receive kidney transplants than Americans, though a limitation to note is that this likely reflects the profitability of continuing dialysis rather than performing a transplant. Overall findings show that more transplants are done in Canada than in the United States across all sorts of diseases (Skala, et al., 2006).

Canada has pioneered an innovative and more risky pediatric heart transplant procedure that involves giving infants incompatible blood type transplantation, thus growing the number of donors young children can receive and transplants able to be performed. This attempt to cross a barrier previously considered impossible arose from a combination of intensive research on

neonatal tolerance and a desperate attempt to save infants with a chance of high mortality if put on the waitlist for too long (Urschel & West, 2016). Using hearts of different blood types allows twice as many organs to be available to type O infants born with heart defects. This approach, once unthinkable, is at least as effective as the traditional process (Rutherford, 2021). Because infants with heart problems already have a very low chance of survival, researchers argue that pushing the boundaries of risks gives patients who would otherwise have no options an opportunity to live (Rutherford, 2021).

To contextualize my research in society, I plan to use theories of technological politics for my STS framework. In "Do Artifacts Have Politics?" Langdon Winner (1980) looks at how society and technology interact. A social determinist, Winner argues, "What matters is not the technology itself, but the social or economic system in which it is embedded" (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 (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 been 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 procedures function. The current systems of both countries are not always malicious in intent but can still discriminate.

Methods

My methods of research include interviews and more literature reviews. I conducted eight online interviews with four pediatric cardiologists from the UVA Hospital and four outside of the local area, including one that is currently working in Toronto. I used these interviews to identify the key differences in the decision-making process of both American and Canadian pediatric cardiologists when looking at a heart donor and recipient. This includes looking at the most important risk factors – what they look at immediately versus what they don't deem necessary, how they define "high-risk", and how past decisions on a heart affect their own. I also aimed to pinpoint the external factors and constraints that pediatric cardiologists have to consider based on the health system they are a part of and use this analysis with the literature review to identify why differences exist and how both can learn from one another. I decided to use this method because this topic is fairly niche and there isn't a whole lot of information comparing the two systems that exist already. I figured that getting answers straight from the people whom these issues are most relevant would be the most effective for my research.

For my literature review, I gathered secondary sources (primarily research articles & journals) that delve into the pediatric cardiologist culture and decision-making process in the United States and Canada. Most of this research was published in the last 20 years or so in medical journals. The goal was to gather evidence on what social and health system factors lead to similarities and differences in pediatric transplant decision-making across not only cardiology but other organ systems as well. This will include insurance and program scoring systems as well as information about kidney and liver transplants. I am broadening beyond hearts because organ

transplants have commonalities in the decision-making process across different organs. Since pediatric cardiology is also a smaller category of a larger healthcare problem, looking at other transplant cultures can help show other perspectives and factors to consider. I wanted to use this method to supplement my interviews by giving more context to the analysis, as there are factors outside of the immediate focus that affect how doctors make their decisions. I was also not able to get in contact with as many Canadian pediatric cardiologists as I wanted to and had to get information about systems outside of the United States in another way.

Analysis

Canadian and American pediatric cardiology programs perceive risk differently, and the reason may lie in the health systems themselves, where the United States and Canada have private and public health insurance, respectively. Uninsured Americans are worse off than their Canadian counterparts, and Americans in the poorest income quintile are more likely to have worse health than their Canadian counterparts. And despite the United States spending more on healthcare per year, the two countries have similar health statuses, and the US has far more inequality (Sanmartin et al., 2020). This can be attributed to the US having a private, multi-payer system, while Canada has a single-payer system that is mostly publicly funded. This means that in Canada, coverage is not dependent on your income or job – everyone receives equal access. Canada even spent 10.4% of its GDP on healthcare; far less than the 17.8% in the US. Canada has also scored better than the US on infant mortality and life expectancy (Rutherford, 2021). As discussed in the literature review, pioneering a procedure to transplant hearts of different blood types in infants shows a healthcare system that is open to taking more chances. This procedure has since been adopted around the world, but for Canada to spearhead its creation displays a penchant for higher risk-taking.

Canadian pediatric cardiologists can use more risk and innovation in their decision-making because they are not restricted by one organization's standards and technology. The United Network for Organ Sharing (UNOS) has been the sole organization responsible for overseeing organ transportation and operations in the United States for over forty years. UNOS has typically encountered little competition for the contract to run the organ transplant system as few entities can coordinate at such a large scale and perform all the organization's other tasks (Editorial Board, 2023). This has led to differences in program scoring and acceptance rates with Canada, as they do not operate under the same organization and thus have different expectations. After interviewing Dr. Malcolm, a pediatric cardiologist with experience with the United States system but currently based in Toronto, the differences were made even more obvious. He explained how Canada has only recently started to use a more automated procedure than just calling organ procurement organizations (OPO), which is far different than the UNOS interface provided in the United States. With this system, Canadian doctors are less likely to fall into the trap of information cascading because they don't see the previous decisions that deemed a heart worthy or unworthy. They are then able to make decisions based on their expertise and are prevented from being swayed by other programs. When talking to pediatric cardiologists working in the United States, I learned that those with more experience learned to take more risks, but overall, the current system discourages them from doing so because there are more hearts available and more proof of previous rejection in the UNOS system.

Riskier heart transplant decision-making is necessary when there are fewer options available and monetary consequences. When I asked Dr. Malcolm if this was the only reason, he stated that often there is no choice and that those are the only hearts available to them in the first place. The politics used in deciding which countries get which donors can be framed using the

theory of technological politics. Health systems naturally prefer to take the first pick in the organs from their area. Although this bias is not always intentional, patients are negatively affected when they are not given access to technology and suitable organs necessary for their survival. Canada receives the hearts that the United States' programs have rejected multiple times, so they are forced to take more risks because they have less of a choice in what hearts they get. Because some of these hearts have been rejected so many times and have thus been sitting outside of the body for a longer time, they actually have more time to stabilize and become a suitable donor. This is another factor that pediatric transplant systems should consider before deeming a donor unacceptable.

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). The demand for heart transplants is increasing more than either healthcare system is prepared for. Though both have strengths in the pediatric cardiac field, Canada and the United States have seen a decline in heart donor usage rates in the past couple of years, indicating that both systems still need improvement (Dharmavaram, 2021). Any substantial changes to either healthcare system could prove complicated or create additional risks to patients because it is difficult to alter what people are used to. However, understanding that the root of these issues is due to organ monopolies and health politics may lead to reform on a smaller scale that will eventually ripple to alter the larger system for the better.

Research about UNOS was primarily taken from a *Washington Post* (a primarily liberal newspaper) article that seeks to disband the organization, so those who favor the current organ procurement system may disagree with my argument. Because the current system has existed for

so long, its creators and typical users may be more resistant to tremendous change. However, there is no denying that there are issues with the way the United States transports and utilizes organs. With no changes being made, the waitlist mortality rate will continue to grow, and the United States could fall behind Canada and other countries in transplant innovation.

Another limitation of my research to consider is that much of the information I was able to find about Canada's system was found from websites made by Canadian universities or hospitals, so there was positive bias towards the way their native country functions.
Given my time and geological constraints, it was also difficult to get the same number of interviewees from both countries. I would have liked to have been able to interview more cardiologists from Canada. Future data scientists should investigate getting more information from Canadian doctors and patients involved in that healthcare system. Research by pediatric cardiologists could also be expanded into looking at the success rates of other countries, as other systems have been able to perform even more transplants than the United States and Canada. This could hone down the reasons behind long-term transplant success. Looking into other types of transplants would help to draw more conclusions on either system as well.

However, even with all the current imperfections, heart transplantations have a high success rate and can save the lives of many children. The future of transplant decision-making will only improve if we can learn from others and past mistakes. Being open to change leaves opportunities for unprecedented growth in the field of pediatric cardiology.

References

Akkina, S., Asrani, S. K., Peng, Y., Stock, P. G., Kim, W., & Israni, A. K. (2012). Development of organ-specific donor risk indices. *Liver Transplantation*, *18*(4), 395–404. https://doi.org/10.1002/lt.23398

Almond, C. S., Thiagarajan, R. R., Piercey, G. E., Gauvreau, K., Blume, E. D., Bastardi, H. J., Fynn-Thompson, F., & Singh, T. (2009). Waiting List Mortality Among Children Listed for Heart Transplantation in the United States. *Circulation*, *119*(5), 717–727. https://doi.org/10.1161/circulationaha.108.815712

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). https://doi.org/10.1111/petr.13764

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, January 27). Behavioral economics—A framework for donor organ decision-making in pediatric heart transplantation. *Pediatric Transplantation*, *24*(3). https://doi.org/10.1111/petr.13655

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, December 8). External validation and comparison of risk score models in pediatric heart transplants. *Pediatric Transplantation*, 26(3). https://doi.org/10.1111/petr.14204

Dharmavaram, N., Hess, T., Jaeger, H., Smith, J., Hermsen, J., Murray, D., & Dhingra, R. (2021). National Trends in Heart Donor Usage Rates: Are We Efficiently Transplanting More Hearts? *Journal of the American heart Association, 10(*15).

Dipchand, A. I. (2018). Current state of pediatric cardiac transplantation. *Annals of Cardiothoracic Surgery, 7*(1), 31-55. https://doi.org/10.21037/acs.2018.01.07

Editorial Board. (2023, March 27). Break up the human organ monopoly. *Washington Post*. https://www.washingtonpost.com/opinions/2023/03/27/unos-hhs-organ-transplant-reform

Fernandez, H., Foster, B. (2022, February). Long-Term Care of the Pediatric Kidney Transplant Recipient. *Clinical Journal of the American Society of Nephrology, 17*(2). https://doi.org/10.2215/CJN.16891020

Godown, J., Kirk, R., Joong, A., Lal, A. K., McCulloch, M. A., Peng, D., Scheel, J. D., Davies, R. R., Dipchand, A. I., Miera, O., & Gossett, J. M. (2019). Variability in donor selection among pediatric heart transplant providers: Results from an international survey. *Pediatric Transplantation, 23*(5). https://doi.org/10.1111/petr.13417

Heart transplant (2022, May 11). Mayo Clinic. https://www.mayoclinic.org/tests-procedures/heart-transplant/about/pac-20384750

Heart Transplant for Children (2021, August 8). Johns Hopkins Medicine. https://www.hopkinsmedicine.org/health/treatment-tests-and-therapies/heart-transplant/heart-transplant-for-children

Khan, A. A., Green, R. C., Lytrivi, I. D., & Sahulee, R. (2016). Donor predictors of allograft utilization for pediatric heart transplantation. *Transplant International*, *29*(12), 1269–1275. https://doi.org/10.1111/tri.12835

Rutherford, G. (2005, March). Pediatric heart transplant method developed by U of A doctors allows for more surgeries, better outcomes. *Folio*. Retrieved October 13, 2022, from https://www.ualberta.ca/folio/2021/03/pediatric-heart-transplant-method-developed-by-u-of-a-doctors-allows-for-more-surgeries-better-outcomes-study.html

Sanmartin, C., Berthelot, J.-M., Ng, E., Murphy, K., Blackwell, D. L., Gentleman, J. F., Martinez, M. E., & Simile, C. M. (n.d.). Comparing Health and Health Care Use in Canada and The United States. *Health Affairs*, *25*(4).

Singh, N., Raees, M., & Zafar, F. (2019, October). Donor considerations in pediatric heart transplantation. *TP Translational Pediatrics*, *8*(4), Article PMC6825970.

Skala, N., & PNHP Staff. (2006, May 17). Previous Studies Comparing Health Care in the U.S. vs. Canada. *PNHP*.

Staff, K. A. W. (2017, May 19). *Is Canada the Right Model for a Better U.S? Health Care System?* Knowledge at Wharton. Retrieved October 13, 2022.

Understanding the Differences in Survival Between Canadians and Americans With CF. (2017, March 13). Cystic Fibrosis Foundation. https://www.cff.org/community-posts/2017-03/understanding-differences-survival-between-canadians-and-americans-cf

Urschel, S., & West, L. J. (2016). ABO-Incompatible Heart Transplantation. *Current opinion in pediatrics*, *28*(5), 613. https://doi.org/10.1097/MOP.0000000000000398

US vs. Canadian Healthcare: What is The Difference? (2021, May 11). Ross University School of Medicine. Retrieved October 13, 2022, from https://medical.rossu.edu/about/blog/us-vs-canadian-healthcare

Winner, L. (1980). Do Artifacts Have Politics? *Daedalus*, *109*(1).