Prospectus

Instantaneous Scoring System for Recipient Survival in Pediatric Heart Transplants
(Technical Topic)

The Political and Economic Role of OneLegacy's Noncompliance in Transplantation Rates
(STS Topic)

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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Sociotechnical Problem

In the United States, more than 400 pediatric heart transplants are performed in any given year (Rossano et al., 2019, 1031). Candidates for transplantation are placed on a national registry and remain in a waitlist status until they receive an offer for a heart. Once a potential donor is declared brain dead, the organ procurement organization (OPO) for the respective hospital will assess the donor and then match candidates on the waiting list in an order generated based on a myriad of factors, including blood type, emergency status, and heart size. The recipient's doctor at the top of the list is then notified by the United Network for Organ Sharing (UNOS) that a heart has become available. If the doctor decides not to accept it, the next recipient on the list is notified, and this process continues until a heart is accepted or discarded (United Network for Organ Sharing [UNOS], n.d.).

This organ donation system rejects 45% of donor hearts that are considered for pediatric transplantation (Gossett et al., 2020, 1). This has contributed to the lengthy time recipients spend on the waitlist, which results in 17% of candidates dying before receiving a heart transplant (Almond et al, 2009). In order to address the inefficiencies of donor-recipient utilization in pediatric heart transplants, my team will propose an instantaneous scoring system that provides the likelihood of recipient survival in one year following the transplant. This will summarize the large amount of data shared with surgeons when they have to decide to accept a donor heart. It will also decrease discarded hearts by providing a standardized and more accurate metric to predict recipient survival, ultimately giving doctors more confidence to accept an offered heart.

However, the technical aspects of the system's design are not the only factors contributing to the failure of UNOS as a socio-technical system to optimize the allocation of organs. Organ procurement organizations (OPOs) oversee the transplant centers that receive

organ donations for surgery and facilitate the matching process and transportation of the organ (UNOS, n.d.). Through misallocation of organs and monetary funds with seemingly no consequence, OPOs also play a significant political and economic role in the recovery and matching process (Zagorin, 2020). Ignoring the unchecked power of OPOs will lead to continued abuse of the organ transplant system as well as inadequate recovery and transplantation rates, even with a technological fix.

Undertaking a solution that encompasses both technical and social understandings will allow a full explanation of why donors may be lost to the system. In order to address the problem's technical aspects, I will propose an instantaneous scoring system of the donor's heart to improve the design by which doctors view donor data to make a transplant decision. I will also use Langdon Winner's Theory of Technological Politics to examine how the lack of oversight by both UNOS and the Department of Health on organ procurement organizations, particularly OneLegacy in Los Angeles, has contributed to low transplantation rates.

Technical Problem

The United Network for Organ Sharing (UNOS) is a non-profit organization contracted by the federal government to oversee the Organ Procurement and Transplantation Network (OTPN), whose goals are to increase the number of organ donors as well as the efficiency and equity of the organ recovery and matching process (UNOS, n.d.). UNOS created an online network called UNet in 1987 to register candidates for transplantation, match them to donors, and input various data, tests, and imaging that has been conducted on donors and recipients (UNOS, n.d.). Within this system is DonorNet, developed in 2014. It uses algorithms to match donors and recipients based on blood type, size, and other factors that are dependent upon the specific organ. It calls the surgeons of recipients who have been matched and shares the donor's

data with them (Boodman, 2016). Those surgeons then have an hour to make a decision (Comparini, 2003). For heart transplants, they examine data on medical history, vitals, laboratory testing, radiological results, and distance from the hospital to assess donor heart functionality and the chance of recipient survival (Organ Procurement and Transplantation Network, 2020, 27).

However, this results in an overload of information provided to the surgeons. It is unclear how much each factor impacts recipient survival, if at all (Godown et al., 2019, 9). If this continues to be the method by which surgeons make decisions to accept the heart, the actual likelihood of recipient survival will remain uncertain. Doctors are even less likely to accept a heart because recipient death will negatively affect a program's funding and standing (Gossett et al., 2020, 1). Donor hearts will continue to be rejected and discarded as they move down the waiting list while candidates on that list die. It has been shown that there is no difference in the success of the transplant surgery and the survival of the recipient for hearts accepted at the top of the list versus those that are accepted later on. Additionally, centers that accept fewer hearts do not have better outcomes for their transplant recipients (Godown et al., 2019, 2). By knowing what data matters the most for recipient survival, physicians will be more confident in accepting the heart. This would lead to acceptance of hearts at a higher spot on the waitlist and a decrease in the number of discarded hearts (Godown et al., 2019, 9). This would ultimately decrease waitlist mortality and increase recipient survival.

My team will be designing an instantaneous scoring system that evaluates the percent likelihood of recipient survival for pediatric heart transplants in one year based on the DonorNet heart data provided by UNOS. We aim to find the metrics most predictive of recipient survival based on the heart functionality of both the donor and recipient. First, we will conduct a longitudinal time study on donor heart functionality from the declaration of brain death to heart

transplant surgery, through statistical and regression analysis. We will then perform an analysis of ultrasound data to evaluate recipient survival. This will allow us to understand how a donor heart's functionality changes over time, and to what extent different aspects of that functionality affect the long term success of the transplant. We will develop a statistical model for recipient survival in one year based on what we determine to be the most predictive metrics in the donor heart data. This model will be used to design a user interface for doctors to view the percent likelihood of recipient survival at the time points at which different tests on and measurements of the donor heart are taken.

STS Problem

UNOS facilitates the process of recipients being matched to and receiving donated organs through its fifty-eight organ procurement organizations (OPOs) located throughout the U.S. that each serves a specific geographic location (US Government Information on Organ Donation and Transplantation, n.d.). OneLegacy is a particular example of an OPO and is located in Los Angeles. It serves 215 hospitals, 11 transplant centers, and a 20 million person population (OneLegacy, n.d.).

When a patient is dying, the hospital will contact the OPO, and they arrange a visit to determine whether the patient is suitable for organ donation. If the patient is considered suitable and is subsequently declared brain dead, the OPO will contact the donor's family. Once consent is obtained from the family and the organ is matched to a recipient through DonorNet, they then coordinate with the surgical team of the transplant center for transportation of the organ (UNOS, 2020). Additionally, they are responsible for educating the public on organ transplantation and encouraging people to become organ donors (Comparini, 2003). As a socio-technical system,

UNOS facilitates organ donation and matching through both its DonorNet algorithms and its OPOs.

OneLegacy, as an organ procurement organization, does carry out these functions for UNOS, but it also performs significant political work, primarily through its OneLegacy Foundation, which is legally unaffiliated and therefore free from any federal oversight. Although the organization was established to carry out OneLegacy's mission to "save and heal lives ..., comfort the families [they] serve, and inspire [their] communities to Donate Life" (OneLegacy, n.d.), it uses Congressional funds and private donations to sponsor floats in the Rose Bowl parade every year (which they submit as Medicare expenses), as well as to serve as experts in Hollywood for various films, television shows, and advertisements (Zagorin, 2020). OneLegacy has also been found to be non-compliant on both donation and transplantation rates, according to Health and Human Services (Medicare and Medicaid Programs, 2019, 133).

If we continue to think that OneLegacy exclusively and successfully engages in organ procurement and education services, we will fail to understand how its private foundation and lack of compliance shape power relations among UNOS, the federal government, and the community which it serves. Drawing on Langdon Winner's theory of Technological Politics, I argue that OneLegacy expresses power relations by privileging the organization, and in particular, its highly paid executives, while marginalizing the communities they are supposed to serve. It does this by misallocating federal funds and private donations through the OneLegacy Foundation rather than making its organ procurement practices and matching algorithms more efficient. By doing so, it fails to meet the necessary metrics for organ recovery, while UNOS and the Centers for Medicare and Medicaid Service implement no regulations to reprimand them (Zagorin, 2020).

Technological Politics seeks to explain how technological artifacts, or systems, are built with either implicit or explicit design aspects that have political consequences. These aspects give power and social status to certain groups while subjecting other groups to the control of the groups in power and ultimately disadvantaging them through their actions (Winner, 1980). I will use the theory of Technological Politics to fully understand why UNOS has allowed OneLegacy to continue to be non-compliant in regards to their organ recovery and transplantation rates. To support my argument, I will analyze reports and audits from the Department of Health and Human Services, letters from California's Congressional representatives on the underperforming OPOs, as well as press releases and tax filings of OneLegacy. This analysis will explore how they are receiving funding, how they are using it, and how it affects the population which it has been commissioned to take care of.

Conclusion

In this report, I outlined the data analytics and statistical modeling that will be used on the DonorNet data provided by UNOS to build an instantaneous scoring system that evaluates the percent likelihood of recipient survival in one year following a pediatric heart transplant. This will encourage surgeons to accept more hearts for transplantation, and ultimately increase recipient survival by decreasing waiting time and allowing more donor hearts to be utilized. By using Winner's Theory of Technological Politics, I will also explore the role of OneLegacy, an organ procurement organization under UNOS that matches donors and recipients as well as transports the organs for transplantation, in order to fully understand how their consolidation of power has contributed to noncompliant transplantation rates.

Both my technological and STS reports will contribute to the larger socio-technical goal of increasing organ transplantation rates and the efficiency of donor-recipient matching. This

requires evaluation of and improvement on how donors are currently matched to recipients, as well as outside political and economic players that affect the number of donors and successful transplant surgeries.

Word Count: 1880

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