How Inequity Was Introduced into The Organ Transplant List

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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

Organ transplantation has allowed doctors to perform life-saving treatments to extend the lives of patients at the end stages of otherwise fatal conditions. In 1984, Congress passed the National Organ Transplant Act (NOTA) (*History and NOTA – OPTN*, n.d.), facilitating the creation of a country-wide registry called the Organ Procurement and Transportation Network (OPTN) to match donor organs to patients in need. In 2022 alone, 42,887 organ transplants were performed in the United States (Young, 2023). However, the supply of donor organs is drastically outpaced by the demand. There are currently over 104,000 people on the waiting list for an organ transplantation in the US. A new person is added to the list every ten minutes, and seventeen people on the waiting list will die every day waiting for an organ (Health Resources and Services Administration, 2023).

In a system that presides over the life and death of countless patients, inequity in the selection process results in deadly discrimination. As early as 1986, research was being published describing inequity in the organ allocation process (Prottas, 1986). Despite this early warning, recent studies have shown that discriminatory practices continue to run rampant in the organ transplant list. People of color are significantly less likely to receive an organ transplant than their white counterparts (*Organ donation and African Americans* 2022), and “black patients and women reported lower rates of referral and later referral for transplantation, poor treatment by medical professionals, and poor education [about their disease]” (Park et al, 2022).

In this paper, I will argue that the foundational legislature governing the OPTN, specifically NOTA and the final rule, and the decisions made by the groups involved in the evolution of the organ transplant list created closure mechanisms that stabilized development towards equitable care. First, I will provide a brief overview of the history of the OPTN and the laws that govern it. Next, I will discuss the sociotechnical framework and methods through which my analysis saw results. Then I will analyze legal texts, academic studies, and news reports to perform a policy analysis and a historical analysis. Through this I will uncover a clearer understanding of how inequity was introduced into the earliest foundations of the organ transplant list and why efforts to eradicate it have been largely unsuccessful. Finally, I will end with a discussion on the implications of this work and how lessons about compromise and enforcement can be applied to new treatment networks.

Literature Review

When the National Organ Transplant Act was passed, it established the Organ Procurement and Transplantation Network (OPTN). However, despite being the creators of the list, the government does not manage it. Instead, in 1986 a private company called the United Network for Organ Sharing (UNOS) was awarded the very first OPTN contract and began managing the list. UNOS has held this contract since (Gentry, 2019). The OPTN, being a nationwide network, is complex and does not solely run through UNOS. There are a total of 398 member organizations in the network, comprised of transplant centers, labs, businesses, medical organizations, and public organizations. 56 of the member organizations are Organ Procurement Organizations, or OPOs (*About the OPTN – OPTN*, n.d.). OPOs are independent organizations from the OPTN and follow their own procedures and policies based on the laws and regulations in their area, which can vary. On a federal level, OPOs are certified by the Center for Medicare and Medicaid Services (CMS) and must abide by their standards (*Organ procurement organizations: Increasing organ donations*, 2024). However, to get access to the national registry of organs and candidates, which is proprietary software, the OPOs must also be members of the OPTN and follow their rules (National Organ Transplant Act § 274, 1999).

It's simple to see how member organizations are regulated by the OPTN, and by extension UNOS, but to understand what or who regulates UNOS, we must investigate the legislature. The policies that governed UNOS's first actions came directly from NOTA itself, yet nowhere in the original writing of this act was equitable care or access to organ transportation explicitly mentioned. In 1986, the Department of Health and Human Services (HHS) began soliciting proposals for policies and procedures regarding the operation of the OPTN (*History and NOTA - OPTN*) after research exposed abundant inequity. 14 years later in 2000, the HHS finally codified and implemented "a final rule" (*History and NOTA – OPTN),* a regulatory framework that outlines how the OPTN should operate and what their core values and goals would be (National Organ Transplant Act § 121.3 *et seq*, 1999). The primary goal of this amendment was to distribute organs more equitably by replacing local organ allocation systems with a nationalized one (*National Organ Allocation policy: The final rule,* 2005). This amendment also explicitly stated that the OPTN would adopt policies that addressed inequity of care between adults and children and stated the intent to increase transplantation rates among populations with special needs, members of racial minorities, and patients with limited access to transportation (National Organ Transplant Act § 274, 1999).

With a new set of guidelines based on over a decade of development, it should be safe to assume that once implemented, the final rule eliminated inequity and discriminatory practices in the organ transplant list. However, a study from 2007 described that uninsured and poor patients on the list still have unequal access to organ transplantation because they cannot afford the prohibitively expensive post-operative treatments (Simmerling, 2007). A study from 2010 found that doctors are still less likely to recommend a black patient for a kidney transplant, and when a black patient does get onto the list, they have longer wait times than their white or Asian counterparts (Malek et al., 2010). Even more recent studies released in 2022 by Park et al. continue to show that these discriminatory practices have not been eliminated simply by passing of legislature.

To better understand why this inequity persists, I will be using the Social Construction of Technology (SCOT) framework developed by Pinch & Bijker. The main idea of this framework is that technology and society are not developed in a vacuum, they influence each other's development and are directly involved in that development. Groups of people who share an interpretation of a technology, called "relevant social groups" (Pinch & Bijker, 1984, p. 414), have interpretive flexibility about what technologies represent. These groups exert influence, often competing, on what problems get solved. As development goes on, interpretive flexibility will decrease, and the problem will be considered solved through either rhetorical closure or redefinition of the problem, a concept known as "closure" (Pinch & Bijker, 1984, p. 424). Eventually, the relevant social groups may decide to stop developing entirely and the technology takes on a form where it is a norm and no more developments are made, a concept called "stabilization" (Pinch & Bijker, 1984, p. 424). I believe that analyzing the decisions made around NOTA, the final rule, and the structure of OPOs through the lens of interpretive flexibility between relevant social groups, closure mechanisms, and stabilization will provide a platform to determine how inequity was fostered and continues to fester in the organ transplant list.

Methods

To gain a better understanding of the relevant social groups, their different interpretations of the list, and the closure mechanisms that stabilized it, I used two different methods. I performed a policy analysis to examine how the laws regulating the OPTN took on their final shape. I collected primary sources comprised of legal texts about the organ transplant list, with a focus on the periods leading up to the passing of NOTA in 1984 and the Final Rule in 2000. I also collected secondary sources such as academic studies and news reports on inequity in the list and attempts to address the inequity throughout time. This allowed me to see where they fell short regarding restructuring or improving the organization of the list and giving all relevant social groups equitable access to the system. I then performed a historical analysis on these sources and reports on management of the OPTN over time to consider whose voices were heard, and whose were not. This allowed me to better understand why inequity was introduced into the organ transplant list and why equitable development of the organ transplant list has been closed to the point of stabilization.

Analysis

The National Organ Transplant Act was passed in a period where the organ transplant community was divisively split. There was friction between transplant organizations and policymakers, and public concern over ethical implications of organ transplantation was tumultuous. However, the passing of NOTA failed to properly account for these issues, and in fact acted as a closure mechanism, impeding equitable development of the list. Prior to the passing of NOTA, interpretive flexibility of organ transplantation was high. Lawmakers in congress were writing NOTA with two main ideas in mind: First, that NOTA was meant to solve a national problem of allocation. There were relatively low procurement rates of donor organs compared to the extremely high demand for them and a high potential availability of organs for collection (Sloan et al., 1989, p. 128). Secondly, NOTA was supposed to avoid privatizing the organ transplant field. This point was a result of public outcry from media and medical professionals over the potential privatization of organ allocation and transplantation, polarized by one event. Late in 1983, shortly before NOTA was passed, a de-licensed physician from Virginia made an inquiry to the Food and Drug Administration about whether they needed a license to import kidneys. This ex-physician planned to solicit and pay donors for their kidneys, and ethical objections to this plan were levied at every step in the process this physician proposed (Gross, 2008, p. 178-179). Public objections to this proposal included concerns over adequate informed consent and issues with the business model perpetuating known economic inequality in the organ allocation system.

However, while Congress was primarily concerned with creating a public, efficient, nationalized allocation system, the transplant community had a different interpretation of the purpose of NOTA. Medical professionals in the transplant community were lobbying to expand reimbursement for transplant therapies, regularizing funding for transplant surgeries (Prottas & Spielman, 1996). Additionally, one specific mode of conflict between individual centers prompted the transplant community to ask the government to intervene. Prior to NOTA, because of localized regulations and practices, some transplant programs were setting up their allocation systems in a way that allowed them to hoard organs to themselves (Prottas & Spielman, 1996). The transplant centers were unable to solve this conflict internally and raised the issue for Congress to address. In 1984 NOTA was passed, leaving the creation and management of the list ultimately in the hands of one individual, the Secretary of the HHS. Title 1 of NOTA also established the Task Force on Organ Transplantation, with a goal to advise the Secretary on the "medical, legal, ethical, economic, and social issues presented by human organ procurement and transplantation" (National Organ Transplant Act § 274, 1984).

This task force would end up having the greatest impact on NOTA's closure of equitable development towards the organ transplant list. After two years of research, they released a report titled "Organ Transplantation: Issues and Recommendations" (Gross, 2008, p. 228). In this 200-

page report, among other suggestions, they recommended the implementation of two specific policies. These policies, once put in place, gave overwhelming power over the list and the members of the OPTN to UNOS. The first policy was a restriction on OPOs, introducing a requirement that they operate exclusively in defined, exclusive service areas because the task force believed that OPOs competing for donor organs would be harmful to the procurement process (Sloan et al., 1989, p. 128). The second policy they recommended was a proposal that transplant centers would be unable to receive any public funding for transplant operations unless they were compliant with OPTN guidelines, to be established by UNOS (Gross, 2008, p. 228-229). By doing this, the task force made being a member of the OPTN a necessity for any transplant center to function and cemented them under the control of UNOS. The issue with this was that UNOS's directives did not always align with those of their member organizations. In the years closely following their appointment, UNOS was interested in increasing and assuring the quality of the transplantation procedures and practices already being done, rather than increasing the equity in allocation, number of transplants operations, or transplant organizations (Sloan et al., 1989, p. 130).

These two policies caused reactionary steps to be taken by some of the relevant social groups involved in the OPTN, which also impeded equitable development of organ transplantation. One example was an action taken by the New Jersey Health Commissioner, who in 1987 attempted to consolidate the three OPOs present in the state to regain some control over the allocation of their state's organs. They were successful, temporarily, because of increased public perception that organ donation was inequitably benefiting people outside the local communities, and created a state-run organ procurement organization (*Delaware Valley Transplant Program v. Coye, 722 F. Supp. 1188, 1190 (D.N.J.* 1989*)*). However, this organization was promptly sued by a prior existing OPO, and during the litigation the only transplant center in southern New Jersey, the area in conflict, was limited in the amount and type of transplants they could do (Gross, 2008, p. 232), directly impacting local patients waiting on the list. Resistances such as this to the nationalized allocation of organs led to an increased inequity in access to organs as transplant organizations fought for control over their policies. There was one more direct result from NOTA itself that set the foundations for inequity. A portion of NOTA allocated funding for kidney transplants for patients with end-stage renal disease, but patients were expected to pay for the prohibitively expensive post-operative immunosuppressants out of pocket. This directly prevented poor individuals from receiving treatment (Gross, 2008, p. 224), demonstrating a clear priority to the transplant operations and a blindness to the needs of disadvantaged patients.

In 1998 when the final rule was first proposed by the HHS, outside reactions to their hardline stance on organ allocation prevented equitable implementation of the act. One specific mechanism of inequity was at the forefront of ethical discussions at the time. Articles and studies were being published describing an increasing disparity in waiting times between states due to UNOS policies that prioritized organs going to patients within the state that it was donated, and only being transferred nationally if there were no eligible patients within the state. One example of this was that patients in Iowa had a median wait time of twenty-eight days on the organ transplant list before receiving a new liver. However, patients in Pennsylvania were waiting a median of 237 days for a liver transplant (Chen, 1999, p. 261). To the HHS, the Secretary, and to UNOS, the final rule represented a solution to this problem. The final rule was a way "…to develop an equitable allocation policy using medical urgency as the primary selection criterion" (Chen, 1999, p. 262). This should have been a landmark development towards equity in the organ transplant list, but not every relevant social group viewed the final rule the same. Many medical professionals in the transplant community believed that the drastic change in organ allocation protocol would have the opposite of the intended effect, claiming that this new allocation system would actually "…lead to lower survival rates, fewer patients transplanted, and longer time on the waiting list for most patients" (Van Meter, 1999).

Congress and various state governments did not view the final rule in a positive light either. To them, the final rule was an overextension of power by the Secretary and the HHS. At the end of 1998, Congress delayed the passing of the final rule for one year, tasking the Institute of Medicine to investigate the final rule and revise it. In anticipation of the final rule eventually getting passed, Congress used this year to pass a bill "…that would take away most of the secretary's authority over the organ transplantation network" (Hussong, 1999). Despite this digging in of heels, the revised final rule was eventually passed and implemented in 2000. However, this revised rule still had the same hardline stance that groups strongly disagreed with, that organ allocation would strictly go to the sickest patients first without regard to state sovereignty over their donated organs. In response to this, seven states "…enacted laws placing restrictions on out-of-state organ transfers, thereby attempting to maintain the status quo allocation system" (Chen, 1999, p. 263). The HHS had predicted that the states would attempt this and had written a clause into the final rule, a federal statute, which "…would nullify any inconsistent state or local law that affects organ allocation policy" (Chen, 1999, p. 273). This back-and-forth power struggle between state and federal legislature prevented much meaningful implementation of the final rule for years. A study was done in 2014 assessing whether the final rule's change, allocating organs explicitly and only by basis of medical criteria and not geographic distance, had an impact on waiting times, transplant rates, pretransplant mortality, and organ quality. Despite specific locations showing promise, “disparities in waiting times, transplantation rates, mortality, and organ quality at the regional and [donation service area] levels have therefore worsened overall” (Davis et al., 2014) in the time since the passing of the final rule.

We now know that the equitable intentions of NOTA and the final rule were not properly implemented, but to understand how that was facilitated we must investigate OPOs. Organ procurement organizations were a primary vehicle for stabilizing inequity in the organ transplant list. The problem began before NOTA: because organ procurement and transplantation is a public, noncommercialized good, OPOs could not be paid for the procurement of organs, only reimbursed through Medicare and federal funding. However, depending on the organ and the level of reimbursement, OPOs could actually lose money during a donor organ recovery, (Howard et al., 2012, p. 12) pushing them towards prioritizing efficiency and prioritizing high value (for reimbursement) organs as a measure of survival. The task force assembled through NOTA was also responsible for limiting the development of OPOs with their introduction of exclusive operating zones and noncompetitive practices. This presented a major issue for already existing OPOs, as many of them covered overlapping regions (Sloan et al., 1989, p. 129). As a result of the new legislation, some OPOs ended up “…entangled in turf wars” (Facklemann, 1985) as they “…battled for designation” (Sloan et al., 1989, p. 129). In 1986, there were 128 OPOs, but by 2012 there were only 58 consolidated OPOs. However, in this time the number of transplant centers increased (Howard et al., 2012, p. 14). OPOs are the first line of contact in the organ recovery/procurement pipeline, and “[a]s the responsibilities of OPOs increased for donor management and education…OPOs [increasingly] interact[ed] with many other health care providers, regulatory bodies, and the public” (Howard et al., 2012, p. 15). In the eyes of the public and the transplant community, “[f]or the past 3 decades, OPOs have been at the center of the circle of donation and transplantation” (Howard et al., 2012, p. 15).

Despite being the epicenter of the organ transplantation list, there has been relatively little enforcement of equitable practices for OPOs. As a matter of fact, even though UNOS is supposed to be acting as an enforcer of the OPOs through OPTN, the members of UNOS who would be enforcing equitable regulations are themselves transplant professionals and members of the OPOs that UNOS would be enforcing (Ornstein*,* 2006). This has created a massive conflict of interest, and the results are obvious: Matt Wadsworth, the head of an OPO in Ohio, claimed in an interview with CBS News that many OPOs nationwide are actually failing, and manipulate their statistics to make their numbers look better than the reality. He even told members of Congress during a hearing in 2021 that many OPOs are “grossly inefficient and unaccountable” (Werner, 2022). Despite this, in the roughly 40 years since the passing of NOTA, no OPO has ever lost their contract with the OPTN (OPO Best Practices, n.d.).

There is one notable resource that a reader may stumble upon which, at first glance, seems to suggest that the OPTN places considerable emphasis on increasing equitable care. If you only took a cursory glance at the Strategic Plans (*OPTN 2018-2021 strategic plan - OPTN*), published every four years by the OPTN Board of Directors, it seems like equitable care is perpetually a main goal in the development of the list as it’s continuously listed as one of the main objectives through the plans from 2018-2027. However, the interpretative flexibility on the definition of equity in organ transplantation between UNOS, the public, and the medical community and a lack of actual enforcement of the plans has led to closure and stabilization of several mechanisms of inequity. UNOS decided in their 2018-2021 strategic plan proposal that the key metrics of equity were to increase the raw number of volunteers involved with the OPTN and to nonspecifically develop "…a common policy framework for geographic distribution of organs…" (*OPTN/UNOS Strategic Plan 2018-2021*, 2018, p. 3). However, public feedback of this plan highlighted how medical professionals in the transplant community believed "…the allocation of resources of only 10% to improving waitlisted patient, living donor, and transplant recipient outcomes and living donor and transplant recipient safety, in reality, cannot support the primary strategic goals of increasing the number of transplants and providing equity in access to transplants" (Rubinstein, 2018). This concern was not addressed by the OPTN Board of Directors for the 2018-2021 strategic plan.

In the 2021-2024 strategic plan proposal, UNOS amended their goal of improving equity in the list to explicitly aim for investigating "differences in access to transplant among different ethnic, economic, and geographic groups" (*Strategic plan 2021-2024*, 2021, p. 6). This change more closely aligned the public perception of equitable development with UNOS's but even then, public feedback came in from OPTN members such as the OPTN Minority Affairs Committee, the Pediatric Committee, and the Association of Organ Procurement Organizations. This feedback claimed that the Board of Directors did an insufficient job in redefining their plans for equitable development, leaving it ambiguous as to whether UNOS was planning to improve equity in health of organ transplant recipients or equity in opportunities for organ transplantation. It was also mentioned that the strategic plan did not actually specifically outline any initiatives to increase equity in getting onto the waiting list or improving equity in quality-of-life post-operation for transplant recipients (*2021-2024 OPTN strategic plan – OPTN*, 2021), which were key issues in the transplant community. Critics of the newly proposed 2024-2027 strategic plan mimic the feedback in 2021, with several comments questioning the lack of measurable metrics to analyze the gains or losses in equity (*OPTN strategic plan 2024-2027 – OPTN*, 2024). Despite making explicit aims to improve equity on all fronts of organ transplantation, it’s clear that to UNOS, the priority has always been the number of organ transplants done and efficiency. By making repeated, sweeping claims about equity without listing performance metrics or specific goals, UNOS has been able to pledge development towards equity without a requirement to actually make meaningful strides in many of the mechanisms of inequity that the public and the transplant community deal with.

Conclusion

Organ transplantation is a miraculous technique that has saved countless lives. However, since its inception the organ transplant list has been fraught with inequity. When creating the initial policies and procedures in NOTA, the lawmakers made short-sighted decisions that closed off development of equity in the list while also introducing new mechanisms of inequity. By restricting the activity of OPOs in the name of reducing competition and placing member organizations of the OPTN firmly under the control of UNOS, lawmakers and the Task Force reduced the interpretive flexibility around the list, with groups prioritizing their own power and survival over equitable care for patients. Throughout the progression of the organ transplant list, UNOS’s scope of equity has been consistently either too narrow or too vague for the interpretations of the public and the medical community. They were unwilling to compromise, to form a socially constructed view of equitable geographic distribution of organs, and took a hardline stance with the organ allocation in the final rule. This stance did not reflect the values of most other relevant social groups, and those groups’ reluctance to accept the final rule further delayed equitable development of the organ transplant list. Despite all this, inequity could have been properly flushed out by now. The primary reason for inequity’s continued existence in the list is an utter lack of enforcement of established regulations and plans. UNOS does next to nothing to enforce that their member organizations follow equity methodologies, and a dangerous precedent has been stabilized into the list where there is little oversight into whether proposed plans for equity are followed.

These revelations have implications that go beyond simply rectifying the current inequities or preventing new modes in the organ transplant list and could be applied to the creation of new treatments. The creation of novel treatments necessitates new networks to facilitate them, and to ensure equitable development of future networks, a socially constructed stance must be created that incorporates all relevant social groups and takes their interpretations into account. However, this is not sufficient alone to ensure equity in these networks. Rigorous enforcement, both internal and external, would help continuously guide the development of the network towards increasing equitable care. Doing so would preventatively address potential sources of inequity to eliminate them before it could be set in motion.

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