The Political and Economic Role of OneLegacy's Noncompliance in Transplantation Rates

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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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Introduction

The United Network for Organ Sharing (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 (United Network for Organ Sharing [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 (UNOS, n.d.).

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).

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, 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.

Background on Organ Procurement Organizations

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.). Once brain death is declared, OPOs are responsible for the medical costs associated with keeping the donor's organs in a suitable condition. For each organ that is donated, OPOs are paid a standard acquisition cost (SAC) for each accepted organ by the transplant center that is accepting them. The transplant center will then be reimbursed by the appropriate insurance, often Centers for Medicare & Medicaid Services (CMS) (Ersoy et al., 2020).

As of last year, OPOs had to meet two of three requirements set forth by CMS in order to be considered compliant. First is that the OPO's donation rate, calculated by total eligible donors per total eligible deaths, is no more than 1.5 standard deviations below the national rate. Additionally, the OPO's donation rate must not be significantly lower than the Scientific Registry of Transplant Recipients (SRTR) calculated rate for more than 18 months, and averaged data reports must meet the most current OPTN donor yield. The OPOs are evaluated for recertification every four years based on these three criteria (Medicare and Medicaid Programs, 2019).

Literature Review

While several scholars have agreed that there is a lack of federal oversight and standardization concerning the financial aspects of organ procurement organizations, which may result in fewer approved organs, no research has emerged concerning where these misappropriated funds are being placed, or how specifically OneLegacy is functioning in this regard. In fact, the literature has praised OneLegacy for increasing designated donors and organs transplanted.

Ozge Ersoy argues that the lack of financial incentives for organ procurement organizations is contributing to the scarcity of available organs. The SAC paid to OPOs is an average cost that is nonspecific to the particular organ or patient, which means it may not accurately reflect the actual costs the OPO incurs from the donor. In addition, CMS may not adjust payments later on to reflect the true costs, and not all costs, such as transportation, are covered by CMS. Because different OPOs have different SACs, to which they are subject to if they are accepting an organ from a different donor service area (DSA), and because transportation costs will be higher across DSA boundaries, an organ may not be procured by the OPO if they believe no transplant centers in their area will accept it, even though another DSA might (Ersoy et al., 2020). While Ersoy mainly explores how true costs may be higher than what OPOs are paid, leading to donor rejection, he fails to consider cases in which true costs may be lower than the SACs the OPO is paid. This lack of oversight could allow OPOs to pocket the extra money for purposes unrelated to organ transplantation.

Ryan Saari and David Cooper delve further into the lack of financial oversight and power of OPOs in controlling their spending through their SACs. Since OPOs are each designated to a specific geographic location with no financial investors or shareholders of which to be mindful, monopolization is essentially allowed to occur, resulting in little effort to keep costs down. The CEO of each OPO has the power to decide salaries, reserves, and spending allocations. The CMS is supposed to oversee expenses, but in reality, each OPO determines its own SAC, and the variability in the SAC between different OPOs can be greater than 100%. Although costs may vary from center to center, this variability suggests a need for stricter oversight and that SACs may not reflect the true cost incurred by the OPO (Saari et al, 2017).

While previous scholars examined organ procurement organizations as a whole, Tomik Vertanous reviewed OneLegacy in particular and suggests that they have been quite successful in increasing designated donors as well as the number of organ transplants, through increasing effective and transparent business practices, as well as educational programs. Their success has allowed them to become one of the largest OPOs (Vertanous et al, 2016). However, this growth may have become stagnated in recent years, and its increased size may leave more opportunities for monopolization and exploitation of funds. This research sets out to explore how the lack of federal oversight may allow OneLegacy to misallocate funds into areas other than organ transplantation and donor registration, such that they have become non-compliant in organ donation and transplantation.

Conceptual Framework

My analysis of OneLegacy's financial misuse draws on Winner's theory of technological politics, which will allow me to understand how an altruistic organization designed to save lives has failed to do so through noncompliance in organ donation and transplantation rates.

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. It is a bridge between technological determinism, in which society changes to accommodate new technology, and social determinants of technology, in which the technology adapts completely to the environment it is introduced to and essentially has no real role in promoting change (Winner, 1980).

While technological artifacts may be hardware systems and innovations that are commonly recognized as "technology", the term also encompasses broader sociotechnical systems in which technology has become intertwined with the environment for which it was intended and into which it was introduced. Winner argues that these artifacts not only have positive and negative properties and consequences, but that they introduce a power dynamic. The political aspect of this theory is social in nature and describing the power dynamic of the groups associated with the technological artifact. The resulting asymmetrical relationship can either be a side effect of resolving a separate problem or an intentional aim to disenfranchise a community (Winner, 1980).

Technologies have classically been viewed as neutral objects with objective uses, and any political consequences that follow are because of the choices of people who use them. However, technological politics makes the claim that there can be implicit biases present throughout the design of a technical artifact such that these political uses become inherently part of it even before being introduced into society. These design choices can be “yes or no choices", or more complex features of the system once they have decided to move forward with it. Another view is the explicit political intentionality that can be a part of certain technologies’ design, and whose use in society is inflexible in causing a power imbalance among the groups it involves (Winner, 1980).

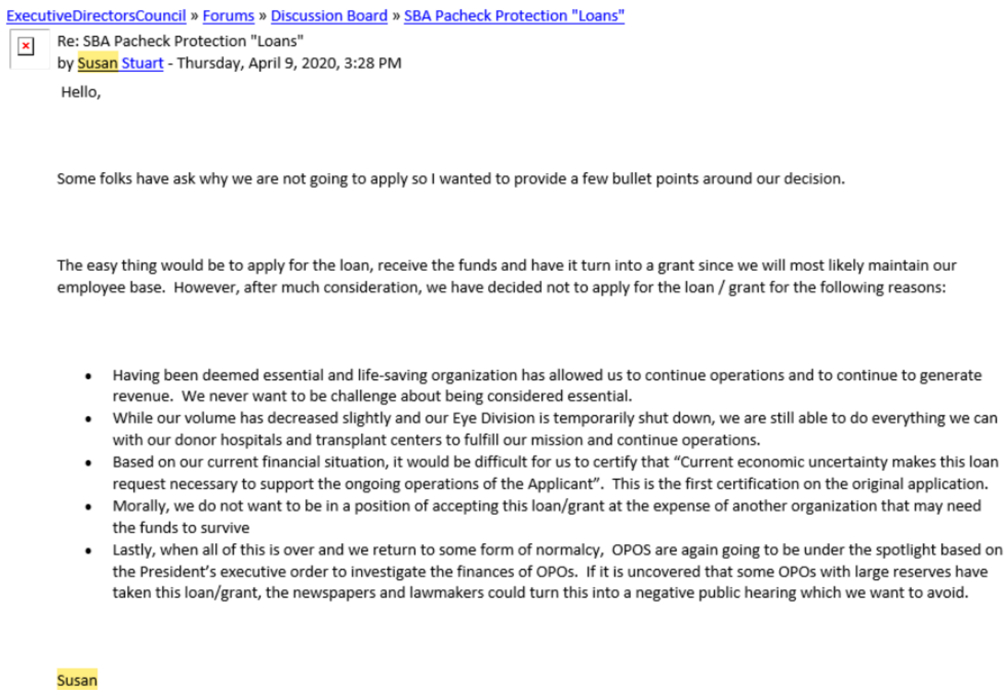
In the analysis that follows, I begin by exploring how the OneLegacy Foundation and its executives have been empowered in the sociotechnical system of organ transplantation, and then I follow with how the designated service area of Los Angeles has been negatively affected and subjected to the monopoly of their organ procurement organization.

Analysis

The OneLegacy Executives as a Privileged Team

OneLegacy expresses power relations in organ donation and transplantation by privileging its highly paid executives without oversight from UNOS. Because of the detrimental effects of the COVID-19 pandemic on small businesses, the federal government initiated the Paycheck Protection Program (PPP) to allow cash flow to those struggling to stay afloat (Zagorin, 2020). According to the Small Business Administration, the OneLegacy Foundation was approved for almost $150,000 in loans on April 30th, 2020 (Small Business Administration, 2020). Earlier that month, Tom Mone, the CEO of OneLegacy, had an email exchange about whether or not to apply for this loan with Susan Stuart, the CEO of another OPO, the Center for Organ Recovery & Education in Pittsburgh. As can be seen from Figure 1, among the reasons she cited for ultimately not applying for the PPP were "having been deemed essential … has allowed us to continue operations and … generate revenue [and] morally, we do not want to be in a position of accepting this loan/grant at the expense of another organization that may need the funds to survive (Brockmeyer, 2020)."

As of 2018, OneLegacy itself had large reserves of approximately $85 million and thus was likely in a similar situation to its Pittsburgh counterpart (Internal Revenue Service, 2018). However, it still ultimately applied for the loan. Although OneLegacy has responded to the press that, "due to our rapid adoption of donor testing and identifying active transplant centers, we were able to continue organ donation as usual … without taking a PPP loan or any other additional federal or private financial support," their loan is still present in the SBA database (Zagorin, 2020). The SBA states with the release of this data that canceled loans are not included. This suggests that not even the actual OPO, but its associated OneLegacy Foundation accepted the loan and is using it to support the activities and expenses of the foundation, despite having a considerable amount of money in reserves and normal organ donor operations during the pandemic.



ExecutiveDirectorsCouncil » Forums » Discussion Board » SBA Pacheck Protection "Loans"

Re: SBA Pacheck Protection "Loans"
by Susan Stuart - Thursday, April 9, 2020, 3:28 PM

Hello,

Some folks have ask why we are not going to apply so I wanted to provide a few bullet points around our decision.

The easy thing would be to apply for the loan, receive the funds and have it turn into a grant since we will most likely maintain our employee base. However, after much consideration, we have decided not to apply for the loan / grant for the following reasons:

- Having been deemed essential and life-saving organization has allowed us to continue operations and to continue to generate revenue. We never want to be challenge about being considered essential.
- While our volume has decreased slightly and our Eye Division is temporarily shut down, we are still able to do everything we can with our donor hospitals and transplant centers to fulfill our mission and continue operations.
- Based on our current financial situation, it would be difficult for us to certify that "Current economic uncertainty makes this loan request necessary to support the ongoing operations of the Applicant". This is the first certification on the original application.
- Morally, we do not want to be in a position of accepting this loan/grant at the expense of another organization that may need the funds to survive
- Lastly, when all of this is over and we return to some form of normalcy, OPOS are again going to be under the spotlight based on the President's executive order to investigate the finances of OPOs. If it is uncovered that some OPOs with large reserves have taken this loan/grant, the newspapers and lawmakers could turn this into a negative public hearing which we want to avoid.

Susan

Figure 1: The email exchange from Susan Stuart, CEO of CORE, and Tom Mone, CEO of OneLegacy, regarding her reasons for not applying to the Paycheck Protection Program (PPP).

It is using its status as an organ procurement organization to obtain federal funding under the guise of using it for its intended mission of improving organ transplantation (OneLegacy, n.d.). The expenses of OneLegacy suggest additional uses of these funds. A 2010 Medicare cost report by the HHS Office of the Inspector General reported $531,460 on unallowable or poorly documented items in 2006, $290,968 of which were unrelated to patient care (United States Department of Health and Human Services[HHS], 2010). A significant amount of costs are also put towards executive salaries. Thomas Mone, CEO of OneLegacy, makes nearly a million dollars in yearly salary (Internal Revenue Service, 2018). Dr. Robert Mendez, Chairman and President, made $109,209 in 2011 while working 10 hours per week on average, and his brother

Dr. Rafaeel Mendez, co-founder, made $33,271 while working 2 hours per week on average (Internal Revenue Service, 2011). The 2010 audit by HHS found that OneLegacy spent $327,000 on the Rose Bowl, of which $150,000 was inappropriate. They submitted these expenses to Medicare which resulted in an $85,000 overpayment (HHS, 2010). This evidence suggests that OneLegacy does not use its funds appropriately.

Instead of using this audit's report to reallocate these funds towards improving organ and tissue donation, they established a foundation in 2011 to manage the expenses deemed improper, such as the Rose Bowl game and parade (OneLegacy Foundation). In the 2018 fiscal year, OneLegacy gave a 10 million dollar grant to the OneLegacy Foundation, which is more than 10% of their total expenses for that year (Internal Revenue Service, 2018). Just last year, the OneLegacy Foundation launched a new website called Donate Life Hollywood. Its purpose is to assist Hollywood by providing videos and experts, among other things, to write accurate storylines concerning organ donation and transplantation. According to a OneLegacy press release, one of its purposes is to gain "publicity support" and raise more money (OneLegacy, 2020). How this raised money is used, however, is unclear.

The results of the 2010 HHS audit did not motivate OneLegacy to establish better financial control. They instead continue to spend significant amounts of their income on executive leadership salaries and raise undeserved public awareness and support through the activities of its foundation (Internal Revenue Service, 2018). As the Office of Inspector General has not pursued a decertification of OneLegacy despite the audit results and lack of appropriate action on their finances, they are in a position of power to mismanage their funds and take advantage of taxpayer money through submitting inappropriate Medicare expenses (Rosenberg, 2018). This absence of accountability while facing noncompliance, from a standpoint of

Technological Politics, has allowed the OneLegacy executive team to inherently corrupt this sociotechnical system, comprised of HHS, OneLegacy, the Los Angeles Community, as well as the organ donation, matching, and transplantation processes. This corruption not only empowers OneLegacy in terms of their financial allowances but deprives the donor service area of Los Angeles by directing money and effort into areas that will not improve their organ donation and transplantation rates.

The Disenfranchisement of the Los Angeles Community

While OneLegacy funnels money into unnecessary expenses, they also express power relations by being non-compliant in acquiring donors and organ transplantation rates and thus disenfranchise the Los Angeles community in need of life-saving operations. Health and Human Services proposed new regulations on organ donations and transplantations, and OneLegacy, in addition to 31 other OPOs, was found to be non-compliant in organ recovery, organ transplantation, organ donation, and new donor rates for all organ types. As seen in Table 1, OnLegacy requires a 9% and 14% improvement in the number of donors and organs in order to be compliant with HHS in donation and transplantation rates, respectively (Medicare and Medicaid Programs, 2019). This is while California maintains the longest transplant waiting list in the United States. Based on OPTN data as of March 11, 2021, it currently has 22,558 candidates awaiting a transplant. While California's population size may be the largest of the states, its population size-waiting list ratio is the third-highest behind the District of Columbia and Massachusetts (U.S. Census Bureau, 2021).

Table 1: Metrics that HHS has found OneLegacy to be non-compliant in, according to the new CMS proposed rules

Metric	*Proposed Threshold*	*OneLegacy in 2017*	*Additional Needed*	*Improvement Required*

Donation rate	4.11	3.47	44 donors	9.02%
Transplantation rate	13.73	11.54	210 organs	14.04%

Self-reporting has also allowed OneLegacy to appear more compliant than they are in reality. For example, OneLegacy reported that it had recovered 69% of potential organ donors from 2012 to 2014 to the CMS (Scientific Registry of Transplant Recipients, 2021). However, only 30.9% were recovered (Goldberg et al, 2017). Lifesharing, a comparable OPO located in San Diego, recovered 154.5 donors per thousand deaths, contrasted to OneLegacy's 93.7 donors per thousand deaths. OneLegacy was able to recover 65% fewer donors than its San Diego counterpart (Scientific Registry of Transplant Recipients, 2021).

The Department of Health and Human Services, as well as the Centers for Medicare and Medicaid Services, offer no reprimanding to underperforming OPOs, including OneLegacy. In fact, CMS has never decertified an OPO, despite many consistently not meeting performance standards (Rosenberg, 2018). In July 2019, President Donald Trump issued an executive order to establish greater oversight over CMS and its constituent organ procurement organizations, in order to address the lack of kidneys available for transplantation (Exec. Order No. 13879, 2019). The CMS proposed new regulations based on objective data measuring the number of organs procured in the donor service area, as well as the organ transplantation rate measure. This will prevent the OPOs from self-reporting data that is incorrect, and further incentivize OPOs to transplant all viable organs; previous metrics were solely based on the number of organs procured. The OPOs will be evaluated every four years, and those that are underperforming the most will not be allowed to renew their contracts (Medicare and Medicaid Programs, 2019). Many in the organ transplantation industry, including UNOS itself, have resisted these proposed regulations. In a recording of a UNOS roundtable that included OPO executives, they discussed the proposed rules and outlined plans to oppose these changes before they were officially passed. In particular, they talked of pursuing a "real congressional action campaign … to reach out to our delegations and weigh in" on the new metrics which they oppose (UNOS, 2020). This perpetuation of zero accountability and underperformance of organ procurement organizations, including OneLegacy, is not only allowed for by UNOS and its associated regulatory bodies but advocated for.

The inaccuracy of self-reported data to CMS, as well as the demonstrated non-compliance of OneLegacy in organ donation, recovery, and transplantation, among others, has led to detrimental consequences for Los Angeles, including incredibly long waiting lists and lack of available organs for transplantation, according to OPTN data. UNOS is aware of this OPO's underperformance and refuses to acknowledge the changes that need to be made in order to increase accountability and increase organ transplants. UNOS, through a lens of Technological Politics, is explicitly oppressing those in need of an organ transplant, and many of those that are in need have no means to combat this mismanagement.

Despite their noncompliance, OneLegacy still boasts of their performance, particularly through increasing their rates in new donors and transplantation over the past few years. In 2020, OneLegacy reported that "2019 marked the fifth consecutive year of record-breaking increases in lifesaving and healing organ, eye, and tissue donation." In 2018, 1,619 organs were transplanted from 557 donors. From 2018 to 2019, there was an 8% increase in organs transplanted per donor. Tom Mone of OneLegacy attributes this increase to improvements in donor registration, family authorization rates, and recovery of organs after circulatory death (OneLegacy, 2020). However, a 2019 study has found that the number of donors dying from drug-related deaths had a 102%

increase from 2009 to 2752 deaths, while non-drug-related deaths actually decreased by 52 deaths. They concluded that the opioid drug epidemic is mostly responsible for the increased number of donors in the United States from 2009 through 2018. This suggests that the opioid epidemic in all likelihood has played a significant role in the increased number of California donors, and within that, OneLegacy's increased donors (Goldberg, 2020), rather than supposed efforts by OneLegacy to increase donors and transplants.

Conclusion

Ignoring the unchecked power of OPOs, particularly OneLegacy in Los Angeles, has led to continued abuse of finances within the organ transplant system as well as inadequate recovery and transplantation rates. I have shown OneLegacy to have mismanaged their financial expenses by overpaying their executive team and submitting grants to their foundation to be used for unapproved activities while being one of 32 noncompliant OPOs through examining the proposed rules and audits of HHS and the tax filings of OneLegacy. By using Winner's theory of Technological Politics, I have framed the actions of OneLegacy and the consequences of those actions to demonstrate that the empowerment of OneLegacy's executive leadership is coupled with the long waiting lists for transplants and the lack of available donors that plague the surrounding community. This new understanding may push UNOS and CMS to realize that the privilege and control they currently afford their OPOs have been severely detrimental to the livelihood and well-being of those they were established to serve. Increased accountability and oversight can help establish appropriate use of funds and increased donor utilization, thereby reducing the asymmetrical balance of power that exists between the organ procurement organizations and the patients of their donor service area.

Word count: 3699

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