

THE COMPLEXITY OF ORGAN DONATION: A REVIEW OF THE LITERATURE

by

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ABSTRACT

This thesis seeks to better understand the factors involved in facilitating or impeding people's desires to register as organ donors. Through an examination of existing literature on the subject it examines issues of altruism, religious beliefs, and trust in the systems responsible for organ donation and transplantation. The thesis also considers the different perspectives offered on these topics by the quantitative and qualitative literatures on these subjects. While increasing education of organ donation and transplantation a primary focus in both literatures, this focus overlooks how factors besides people's knowledge of transplantation impacts the decisions they make. Religion is another factor that is often studied. All major religions accept donation practices, but many individuals cite religious beliefs as reasons not to donate. Likewise, altruism is identified as the biggest perceived benefit of donation, and medical mistrust is a major reason many choose not to donate despite adequate knowledge of donation and its benefits. Within the qualitative literature, narratives from surgeons, donor families, and recipients provide unique insights into these issues that are largely absent in the quantitative literature. Ultimately, this thesis finds that transplantation, and especially the quantitative research on this subject, is heavily skewed by the worldview of biomedicine, one that views the body as a machine with replaceable parts that can be fixed. In order to increase organ donation rates, especially in communities that lack trust in the medical field, systematic change is needed. To accomplish this those that lead organ donation efforts must first recognize the underlying issues that prevent organ donation and then work to make changes to the system so that those issues are appropriately addressed and mitigated.

I. INTRODUCTION

Nationwide there are over 106,000 people waiting for an organ transplant, yet in 2020 only 39,000 transplants were performed (HRSA, 2021). A national survey of donation attitudes and practices found that over 90% of people in the U.S. have favorable views of organ donation, yet only 60% of these individuals (approximately 156 million) were registered as organ donors. Complicating this situation, only 3 in every 1,000 deaths occurs in a manner that is suitable for organ donation, further straining the supply. To increase organ donation, research has repeatedly sought to assess the discrepancy between cognitive perceptions and behavioral outcomes in an effort to increase organ donation and alleviate the healthcare crises created by the organ shortage. This thesis reviews this existing literature to better understand the factors facilitating or impeding individuals from registering as organ donors. These study individuals are doubly important as they may also be involved in making decisions for their family members.

Understanding considerations related to organ donor registration is an important aspect of increasing donation rates. This is true for individuals choosing to become organ donors and for family members who may be approached about organ donation following the death of a loved one (Shah et al., 2018). The United States employs an expressed consent (“opt-in”) system of organ donation (Zink et al., 2005). Thus, an individual must explicitly state at the DMV or through online donor registries that they wish to donate; this decision is considered first person authorization. Registration status is especially important in the US because all 50 states, including the District of Columbia, have enacted the Uniform Anatomical Gift Act of 2006 that makes first person authorization legally binding (Traino & Siminoff, 2013). Consequently, OPOs do not need to seek

consent from family members of a designated donor, but they do inform the family of each individual's legally-binding decision. Although donor registration will be the main focus of this paper, many factors dictate this decision. The examination of altruistic motivations, religious beliefs, trust in the system, and narratives of involved individuals will support the understanding of organ transplantation as a whole.

In analyzing the existing literature on organ donation and transplantation, it is important to recognize the two approaches used and how they compare and contrast. Quantitative research is the most common. This research attempts to prove or disprove a hypothesis based on the data collected (Arghode, 2012). To do this, it seeks to quantify participant responses with numbers and interpret them through statistical analysis. Qualitative research, however, explores the meaning of the topic as understood by participants. Consequently data collection involves interviews and observations to capture the perspectives of participants and analysis involves assessing meaning as described by the participants, instead of meaning being imposed by researchers (Arghode, 2012). Within transplantation, quantitative and qualitative methods are rarely used together. It is possible this is an artifact of who conducts the research. Quantitative research is often produced by medical schools and their associated professionals. Meanwhile, qualitative research is most often produced by anthropologists and other social scientists. Both are crucial to understanding the complexities of the donation process. Ideally, qualitative data can gather unbiased perspectives of people's attitudes to then guide quantitative surveys.

This thesis reviews both quantitative and qualitative literature in conjunction with each other to bridge the schism that currently exists between the two approaches by

discussing the factors that are most often cited as determining donation. These factors include education and knowledge, religion, altruism, and medical trust. It will also recount narrative perspectives of individuals directly involved in the transplant process. It will discuss the problematic nature of qualitative approaches from a theoretical standpoint and the limitations of quantitative literature. Lastly, it will conclude by summarizing potential methodological revisions that could increase registry numbers to help alleviate the organ shortage in the United States and around the world.

II. KNOWLEDGE AND EDUCATION

Knowledge of organ donation is consistently a variable in quantitative studies and a large focus of qualitative studies. Interpreting the general public's knowledge and understanding of donation is important to researchers because a supposed lack of knowledge can be solved by increasing educational efforts. As a result, an intense focus on education as a method to alter attitudes and change organ donation behaviors is superficially proposed because as Li et al. (2013) explain, "Education [regarding organ donation] is a non-controversial solution." This idea is boasted as numerous studies report an increased understanding of organ donation correlates with more positive attitudes (Wakefield et al. 2010). Additionally, knowledge of organ donation increases willingness to donate, and this is a key distinction that separates cognitive thoughts from behavioral action. Knowledge of organ donation in the literature also extends to knowing an organ donor, transplant recipient, someone waiting for an organ, or someone registered to donate. A study by Rumsey et al. (2003) surveying a small midwestern university found knowing someone who donated after death accounted for 4.77% of the variance among the study's Organ Donation Attitude Survey, and knowing an organ recipient accounted for 1.32% of variance. The same study also found that overall knowledge and education yielded the highest variance in the survey at 15.82% (Rumsey et al., 2003). Despite education's importance among organ donation behavior and attitude, the prevalence of this variable in quantitative and qualitative literature is unsuspectingly, but sometimes explicitly, tethered to the over reliance on the Health Belief Model.

The Health Belief Model (HBM) is a multi-faceted theory that explores an

individual's beliefs on health and disease (Pauli et al., 2017). It originated from social psychologists exploring why people were not participating in programs designed to prevent and detect disease (Champion & Skinner, 2008). However, over time the model has been extended to study broader public health concerns including attitudes and behaviors regarding organ donation in the context of a nationwide organ shortage. In this regard, the Health Belief Model identifies factors that influence decisions related to an individual's decision to register as an organ donor. As Quick et al. (2012) explain, a key focus of the HBM in this context is to improve dissemination strategies to communicate the need for organ donors. To achieve these goals, six constructs constitute this theoretical approach: severity, susceptibility, benefits, barriers, self-efficacy, and cues to action (Quick et al., 2012).

Analyzing the individual constructs of the health belief model reveal how heavily skewed the theory is towards education as a (the) solution. Of the six constructs, half represent analogous concepts relating to knowledge and education. The severity construct investigates perceptions of the need for more organ donors, and the susceptibility construct investigates the perceptions of being personally impacted by organ donation (Quick et al., 2012). Together these constructs are labeled as the perceived threat (Champion & Skinner, 2008). Pairing these constructs together also draws on the two psychological learning theories of which the HBM was founded: stimulus response theory and cognitive theory (Champion & Skinner, 2008). Understanding severity confirms the need for organ donors as quantified by organ procurement organization statistics, but coupled with susceptibility, a global threat is transformed into a personal threat. This perceived threat is consequently twofold. Cognitively, there is an expectation

that registering as an organ donor can reduce the organ shortage, yet behavior can be reinforced by perceived personal consequences and/or experiencing the personal consequences of ill family and friends in need of a transplant.

The HBM provides the theoretical framework for focus groups that were conducted by two different studies. The first, conducted by Quick et al. (2012), focused on perceptions among African American, Hispanic, and White high school students. The second, conducted by Williamson et al. (2017), investigated the perceptions of African Americans 18 to 78 years old. Qualitatively, understanding the severity of the organ shortage of Quick et al.'s (2012) high school participants varied widely. When asked for estimates of the potential number of patients in need of an organ transplant, the answers varied from 1,000 to six million (Quick et al. 2012). Meanwhile, participants in Williamson et al.'s (2017) study were all aware of the organ shortage and the need for more organ donors. Susceptibility perceptions were more congruent between the different studies. The majority of participants of both studies perceived a high probability that themselves or a family member would need a donated organ at some point in their lives (Quick et al., 2012; Williamson et al., 2017). These perceptions were based both on abstract senses and personal experiences knowing someone who needs or received a transplant. The personal experiences with ill family members of a few high school study participants influenced their perceptions of susceptibility and illustrates the stimulus-response theory that guides the HBM (Quick et al., 2012).

The last construct of the health belief model focusing on education is the "Cues to Action" construct (Quick et al., 2012). When applied to organ donation, this construct describes various messaging strategies to mobilize individuals to register. The cues to

action construct has guided quantitative researchers to consider educational-based programs (Li et al., 2012) and qualitative researchers to ask focus group participants to provide feedback on how campaign strategies can be more effective and improve registry rates (Quick et al., 2012).

One of the differences between quantitative and qualitative studies regarding education is quantitative studies less explicitly follow the HBM; the qualitative studies, mentioned in this section, directly follow the HBM constructs when structuring focus group discussions. Despite this difference, the influence of the HBM is problematic in terms of organ transplantation because it skews the research foci to knowledge/education. Although authors may conclude that education improves attitudes and willingness regarding donation, this does not translate into behavioral changes. When qualitatively assessing barriers to registering for donation, researchers all noted the perceived barriers outweighed the benefits of donation which were conveyed through increased knowledge of transplantation (Quick et al., 2012; Williamson et al., 2017). Qualitative studies have the potential to challenge survey data through a more intensive understanding of individuals' concerns. Williamson et al. (2017) even recognize these concerns as they note African Americans' mistrust of the medical system encompasses a "much broader, more institutionalized, and systematic discrimination" against their community. However, their perception of potential solutions to these beliefs is drastically skewed by the HBM, and they conclude by offering additional educational resources and dissemination strategies to increase registration rates.

In contrast to the HBM's focus on education is Radecki and Jaccard's (1997) review of psychological aspects involved in individuals choosing to become (potential)

organ donors. This article provides a theoretical framework for analyzing donor behavior. The general framework states that individual beliefs determine attitude toward organ donation. Attitude determines willingness to donate, and willingness to donate determines one's commitment to donate, as evidenced by official registration. Interestingly, Radecki and Jaccard (1997) identify five different beliefs that influence attitude: religious, cultural, knowledge, altruistic, and normative (Radecki & Jaccard, 1997). This could be a potentially useful theoretical approach that seems more tailored to the specific concerns regarding donation. This theoretical approach has even been mentioned in guiding a quantitative survey, but only two of the five beliefs (knowledge and religion) are explored in the study (Rumsey et al. 2003). Rumsey et al.'s focus on knowledge and religion exemplifies the powerful influence that the HBM holds in this field of study, but this focus also exemplifies biomedicine's search for a "quick fix" to changing beliefs and therefore behaviors.

Lastly, Radecki and Jaccard (1997) note organ donation research lacks a strong theoretical foundation. This observation is supported by a systematic literature review finding 22 of the 33 articles reviewed did not have a theoretical theory specified (Wakefield et al., 2010). Given the resulting lack of knowledge and structure of such studies, there is potentially a "niche" within the field for the health belief model as a theoretical framework. Although the HBM may easily fill a need for theoretical structure in the field, the ethically-fraught nature of organ transplantation challenges the utility of this framework. The following sections more closely align with Radecki and Jaccard's (1997) theoretical theory to explore the different beliefs that shape attitudes and ultimately influence registration rates.

III. RELIGION

According to Radecki and Jaccard's (1997) theoretical model described previously, religious beliefs can affect one's attitude toward becoming an organ donor. Religion has been studied in various quantitative studies to determine the effect of such beliefs. Three main ideas result: first, major religious faiths transmit positive attitudes of organ donation (Gillman, 1999). Second, despite these favorable attitudes of donation, many potential donors cite their faith as a reason to not donate, and lastly, religious leaders can influence their congregants' decisions about donation (Holman 2012; Gallagher, 1996).

One of the most prominent reasons that individuals cite not wanting to donate is a belief that bodies must stay intact for the afterlife/resurrection (Gillman, 1999). For some faiths, like Buddhism and Hinduism, that believe in reincarnation or continual rebirth this is not an issue. The Hindu position on organ donation is one of personal choice, though Hindu mythology includes stories of using body parts for the benefit of others (Gillman, 1999). Buddhism does not have an absolute stance on donation, but the tenant of compassion within the religion aligns well with donation's principles. Among the Sikh community, there is also little resistance due to a tradition of altruism among these followers (Gillman, 1999).

Of the monotheistic religions, the three main branches of Christianity (Catholics, Protestants, and the Greek Orthodox all support donation (Gillman, 1999). Moreover, Catholics and Protestants accept brain death as a satisfactory definition of death (Tarabeih et al., 2020). In contrast to the Christian view, followers of Judaism view the

body as a “holy vessel,” which has historically caused resistance to donation (Rumsey et al., 2003). Additionally, body mutilation equated to tampering with God’s divine image (Rumsey et al., 2003). This view is challenged by the Jewish legal principle that affirms saving a life takes precedence over all other laws (Gillman, 1999). Lastly, Islamic beliefs support donation for the purposes of saving a life, but some opposition stems from injuring the wholeness of the body (Tarabeih et al., 2020). Overall most religions value altruism and generosity, so there should be little resistance to donation.

Despite these positive attitudes of donation from many different religious faiths, many individuals still cite religion as their reason for not donating (Boulware et al., 2006). Underlying this contradiction is firstly a lack of awareness about their religion’s position on organ donation. A survey of over 800 participants of three different monotheistic religions in Israel revealed that there were no significant differences between faiths, but there was an overall low willingness to donate (Tarabeih et al., 2020). These authors deduced that “large numbers of believers are confused” about how donation is viewed, officially, within their religions (Tarabeih et al., 2020, p. 5).

This confusion can be addressed by religious leaders. Multiple quantitative studies noted the importance and influence of religious leaders in shaping the attitudes on donation (and therefore willingness to donate) among their congregants (Gallagher, 1996; Tarabeih et al., 2020). A study among religious leaders, hospital chaplains, and seminary students, totaling 420 participants in Colorado and Wyoming, found that over 90% were comfortable discussing organ donation and counseling families on the matter (Gallagher, 1996). Additionally, a significant percentage of chaplains (80%) and clergy (54%) surveyed said the public has asked about their professional opinion, and over 85% of

each group did not view organ donation as body mutilation, which can be a concern for the public (Gallagher, 1996). Overall, Gallagher (1996) suggests that religious leaders have the capacity to discuss death and donation to guide and educate grieving families in this process.

Although religious leaders can often facilitate donation, there are rare cases where they can undermine this utility. Gallagher's (1996) study described above found that 25% of all respondents were uncertain or agreed that organ donors were not really dead. This finding can potentially hinder their opinions of donation while also understanding its benefits. An international study of 468 Turkish religious leaders found that although 90% believed in the importance of organ donation, only 5 participants (1.1%) had actually signed an organ donation card (Güden et al., 2013). Additionally, only one-third of these participants tried to educate others on donation, and only 3% successfully convinced people to donate (Güden et al., 2013). This study was a particularly extreme instance of the difference in attitude and behavior but reveals the influence of attitudes and behaviors of such leaders.

A qualitative study by Hodge, Bellander, and Norman (2011) exemplifies the importance of religious leaders' influence to facilitate donation. At a two-day symposium workshop focused on raising awareness of organ donation among American Indian communities in Minnesota, the authors analyzed perceptions of donation among American Indians and the discussions between Western healthcare providers and this group (Hodge et al., 2011). Like many other religions, there was a fear of breaking tribal taboos by donating. However, by facilitating conversations between American Indian healers and Western healthcare professionals, knowledge of the process and reassurance

in the act of donating could be shared with the community.

When analyzing the discussions between Western health care providers and spiritual healers at the conference, it is important to recognize that in some societies religion *is* medicine. Spiritual healers in these community typically use their spiritual influence/power to address health issues within their communities. Throughout the conference, the biomedical worldview and culture, which is so drastically different from the traditional American Indian worldview, was imposed on the participants. Western healthcare providers found knowledge to be one of the biggest barriers to donation; the need for knowledge was one of the biggest themes identified by the researchers (Hodge et al., 2011). Throughout the conference, healthcare providers shared information of transplant surgery, protocols for donation, return/disposal of remains, and post surgery care. Increasing knowledge, however, does not address the cultural and spiritual dimensions of donation and reception. One healer explains, “Our spirit resides in our body” (Hodge et al., 2011, pg. 85). By accepting organ donation and reception, this community must incorporate the biomedical view of their body into their existing cultural and spiritual beliefs. For American Indians, spiritual healers become the best people to bridge this gap.

Recognizing these types of dynamics can explain why it is often difficult to capture the dynamics of religion through quantitative surveys. By categorizing survey participants into religious groups, the nuance of each religion and individual differences of practice is ignored. Moreover, the culture of biomedicine, which views bodies as machines with replaceable parts, has a pertinent influence on these surveys. This understanding can explain why the answer to the contradiction between religious views

and individual willingness is often attributed to a lack of information. Ultimately, the body and our views of our bodies are intertwined with religion, culture, and society which are absent in quantitative studies stemming from a biomedical perspective.

IV. ALTRUISM

Identified both quantitatively and qualitatively, altruism is often the main perceived benefit of donation. Focus on the altruistic perceptions of donation are often perpetuated by the organ donation system itself through the promotion and construction of a “gift economy” (Sharp, 2001). This explains the willing exchange of organs without an expectation of monetary compensation. The “gift economy” not only obscures the commodification of each organ but has resulted in altruism being the most pervasive benefit of organ donation (Quick et al., 2012; Williamson et al., 2017).

Legislation explicitly outlaws the direct sale of human organs in the United States, yet commodification is central to the success of organ transplantation. Transplantation would not take place without financially supporting the sophisticated technology and personnel that allow for successful procurement and transplantation. The money that flows into this specialty explains why transplantation is the highly developed field of medicine it is today and why some hospitals can support entire transplant wings. Given the current legislation, OPOs must mask the commodification of organs through prolific rhetoric that almost exclusively describes organs as “gifts of life” (Sharp, 2006). Masking the reality of monetary exchange in this process even presents itself through the corporate names of many organizations which include, *LifeGift* of Houston and nationally, *Donate Life America*. Through these constructions, decommodification becomes a central and forced point driven by OPOs. By restructuring the commodification of donors, OPOs can appeal to the public’s altruism to mitigate the organ shortage. Yet even when money *is* exchanged at various levels by insurance companies, patients, hospitals, and OPOs, it never explicitly covers the cost of the organ

itself; instead it covers “technical, transportation, and other support services” (Sharp, 2006, p. 31). Although the actual transfer of money in transplantation is less visible unless directly involved, the avoidance of commodification continues to assert the “gift of life” idea which casts harsh judgments on those not willing to donate.

Altruistic motivations are often a focus in quantitative studies. One study showed that persons with high willingness to donate, as indicated by previously registering as a donor, were statistically less likely to be in favor of incentives for donation including financial reimbursement for medical or funeral expenses, a certificate of recognition, or cash payments to family or a charity of choice (Boulware et al., 2006). Additionally, a quantitative study from Poland showed that there was a correlation between lack of empathy (as tested by Mehrabian and Epstein’s Measure of Empathy) and unwillingness to donate (Wilczek-Ruzyczka et al., 2014). Both findings imply the importance of altruism in the matter. This is reflected by Boulware et al.’s (2006) study participants who noted concern that monetary compensation could erode the perceived altruistic features of donation.

The saturation of this selling point makes the benefit of organ donation clearly understood by the public. As one African-American study participant mentioned when discussing the perceived benefits of donation, “It’s all about giving back. It’s love...With the last breath of my life, I want to help somebody” (Williamson et al., 2017, p. 204). Despite this conviction, this individual was not a registered donor. This contradiction is most likely based on multiple factors dissuading this individual from donating, but Ladin et al. (2015) propose community factors, like social capital, may factor into one’s altruistic motivations to donate.

Ladin et al. (2015) discuss the social capital perspective that views organ donation as a form of civic engagement like voting, volunteering, and community participation. Their theory proposes that social capital, which includes a sense of solidarity, moral obligations, and social values, has a direct impact on the number of organ donor designators in various communities. These conclusions were drawn by studying the Massachusetts Department of Transportation Registry of Motor Vehicles and linking the data to the 2010 Census (Ladin et al., 2015). Factors including residential segregation, voter registration/participation, residential mobility, and violent death rate helped measure social capital levels (Ladin et al., 2015). Ultimately, the authors conclude that more than half the variation in donor designation is due to community-level factors, as opposed to individual-level factors like education (Ladin et al., 2015). This study is particularly useful as it frames the main motivational factor to donate, altruism, among multiple community-level factors instead of the often individual-level factors that are studied extensively.

Broadening the perspective as Landin et al. (2015) propose not only provides potential solutions to increasing donation rates across multiple communities, but it can break the self-created problem within organ donation that positions minority groups as the “problem” to organ transplantation. As pointed out in multiple studies, a paradox exists within transplantation. Specifically, communities most in need of transplants have very low donation and donor designation rates (Ladin et al., 2015). Medical anthropologists, Kierans and Cooper (2011), reveal that low donation rates among certain populations (Black and minority ethnic, BME, communities) may be due to the specific ways in which the transplant system targets these groups. By consistently appealing to the

morality of helping others within the distinct racial and ethnic communities, transplant organization reinforce the differences between groups and further perpetuate the existing paradox within donation. By investigating the problem through social capital, we can separate such entrenched ethnic boundaries and view the problem through a broader environmental and community lens, less focused on biological differences between ethnic groups.

Interestingly, as OPOs in the UK emphasize donation as a method to giving back to one's community, this factor in donating is not lost among US populations, specifically Black communities. A few African-American focus group participants mentioned that they would love to donate organs directly to other African-Americans. Simultaneously they believe the increased number of African-American recipients on the waiting lists is evidence of a "rigged" system working against them (Williamson et al., 2017). Understanding these dynamics proves altruistic motivations are not lost among minority populations, but instead other stronger and deeper factors are working against the altruism of donation.

V. MEDICAL MISTRUST

Medical mistrust is a major factor that often underlies individuals' hesitation or outright refusal to donate their organs. The mistrust ranges from fear of inadequate medical intervention if one is a registered donor (Quick et al., 2012) to conspiracies tying police brutality with supplying the organ shortage (Williamson et al., 2017). Medical mistrust has historical precedent that has bruised some individuals', and permanently scarred others', outlooks of organ donation and transplantation. Unfortunately, the transplant system inadequately addresses systemic and historical injustices that create medical mistrust and skepticism towards donation. Instead the focus is on how low donation rates are a result of individuals' lack of knowledge on the process and its benefits.

Underlying medical mistrust, particularly the fear that medical professionals will not try as hard to save a registered organ donors life, is the transplant system's own emphasis on the organ shortage. As Sharp (2001) points out, there is scarcity anxiety that underlies procurement efforts. However, procurement efforts focus solely on the supply side, burdening the public with remedying the organ shortage, and ignoring the increasing number of patients being placed on the waiting lists by surgeons (Sharp, 2001). This skewed attention on increasing donation rates also drives the academic efforts in quantitative and qualitative literature; it's unlikely to read an article on donation without mentioning the number of people on the transplant waiting list. Fundamentally though, the scarcity anxiety driven by OPOs creates just that, anxiety. However, this anxiety is counterproductive to donation's cause since a portion of the population is now fearful of the healthcare's system presumed eagerness to remedy the shortage.

Scarcity anxiety created by the transplant system itself is the hidden undercurrent to the much more visible international event that created mistrust that lingers abroad today. The Wada Case in Japan was the first heart transplant in Japan that transformed into a murder investigation (Yasuoka, 2019). In 1968, Dr. Juro Wada administered a muscle relaxant to a drowning victim who recovered spontaneous breathing in the ambulance on route to the hospital. Additionally, the heart recipient was not sufficiently critical enough to require a heart transplant (Yasuoka, 2019). Even more concerning, Dr. Wada conducted the brain death evaluation of the donor, selected the recipient, and conducted the transplant against a colleague's advice (Yasuoka, 2019). This was a devastating blow to heart and liver transplantation in Japan which was halted for the next thirty-one years (Yasuoka, 2019). Additionally, determining Dr. Wada's guilt (or innocence) in the ordeal was impossible following the destruction of all documents relating to the case (Yasuoka, 2019). This case resulted in direct mistrust in Japan's transplant system and the lowest transplantation rate among industrialized countries today (Yasuoka, 2019). Although the Wada case took place in Japan, the resulting mistrust surely spread across international borders at the time, and is a direct example of many people's concerns that doctors will not save people who are registered donors (Williamson et al. 2017).

In the United States mistrust in the medical system also exists due to historic injustices fueled by the institution of slavery that has created stark health disparities today. Author Harriet Washington writes in her book, *Medical Apartheid*, of the long and dark history of Black bodies being used for scientific experimentation. A few events include: the unanesthetized surgical experiments of enslaved women leading to the

founding of modern gynecology, the well-known Tuskegee syphilis experiments, and the lesser-known horrors of the Holmesburg Prison complex which elevated the field of dermatology under Dr. Albert Kligman (Washington, 2006). These all contributed to the view of disposable Black bodies that fuels medical mistrust and skepticism towards organ donation. This fear is exemplified within many African American focus groups. In an examination of their qualitative study of African Americans' perceptions of organ donation, Williamson et al. (2018) identify four types of medical mistrust in African Americans' sentiments: societal distrust, distrust of institutions, distrust of medical institutions, and organ donation specific distrust (Williamson et al., 2018).

Societal distrust was embedded among experienced and witnessed societal discrimination toward African Americans and historical discrimination and oppression (Williamson et al., 2018). One woman's grandparents commented that organ donation was not a good idea because their ancestors had been wronged and held back from being socially mobile. She stated, "And we're going to give our organs to someone who's privileged or had more. I'm not going to do that" (Williamson et al., 2017, p. 205). Distrust of institutions also existed due to a history of, and continued experience with, systematic discrimination including a belief that physicians had genocidal motives (Williamson et al., 2018). Organ specific concerns mainly revolved around the belief many participants held that they would receive less adequate care if a known donor (Williamson et al., 2018). This last concern is shared among other racial groups, but it is clear that for African Americans, concerns about a premature declaration of death does not provide a full picture of the perceived barriers to donation.

In discussing the multi-faceted nature of mistrust for African American

individuals, Sharp validates some of these concerns by noting, “Young men and boys of color who are victims of street violence can be a significant source for donated organs” (Sharp, 2001, p. 119). Specifically, 20% of all donors were in the United States were from gunshot wound and stabbing victims (Sharp, 2001). This fact is rarely discussed by procurement professionals and even denied by the same individuals. This statistic proves that colored bodies are silently driving organ procurement efforts in the United States today. Sharp’s observation consequently details the challenge faced by organ procurement leaders to create targeted campaigns for African American communities. Since concerns and mistrust are historically and socially rooted, change must first be initiated by organ procurement organizations themselves by talking about the violence that frequently drives their work. Understanding the systemic injustice that has plagued the grieving family members of a brain-dead donor must be met with understanding and more importantly respect by organ procurement professionals.

VI. NARRATIVES OF INVOLVED PARTIES

At the crux of organ transplantation is the donor. Without this new medically-specific agent, suspended in a ventilator-dependent stasis, organ transplantation would not exist. However ambiguous the personhood of the donor, their organs function biologically and thus hold power over transplant surgeons, coordinators, recipients, and donor families (Yasuoka, 2019). This section focuses on illustrating the narratives of each concerned party. These narratives are largely absent from quantitative literature but provide rich insight to more fully understand the complexity of organ transplantation that ultimately shapes the attitudes and behaviors of potential donors.

Dr. Maria-Keiko Yasuoka explores organ transplantation in Japan and interviews multiple involved parties in her research. Organ donation remains low in Japan, largely due to the history of transplantation in the country specifically the Wada case mentioned previously (Yasuoka, 2019). Consequently, transplantations in Japan rely more heavily on living and overseas donors than in the United States (Yasuoka, 2019). Regardless narratives still provide perspectives on Japanese reactions and feelings in response to the universal medical issues that transplantation creates.

Transplantation in Japan has shifted the culture of medicine, particularly abandoning the traditional paternalistic relationship of surgeons to patients (Yasuoka, 2019). The role of Japanese surgeons is now more similar to those in the United States, acting as mediators between donors and recipients. Surgeon narratives allow greater understanding of transplantation's impact as an emerging and highly specialized technology. The views of surgeons differ depending on which organ they specialized in, but a common

denominator between each specialty is a focus on the revitalization of recipients, which drives their work (Yasuoka, 2019). Heart surgeons in Japan alter their perspective of transplantation with more effort than liver and kidney surgeons to solely focus on saving the recipient's life as they physically stop the donor's heart during the recovery process (Yasuoka, 2019). As one heart transplant surgeon reports, "I feel that I gave them [the donor] the finishing blow!" (Yasuoka, 2019, p. 22). Another Japanese heart surgeon mentioned going out for drinks with an American heart surgeon and discussing leaving the field due to the mental and physical tolls. Despite this the surgeon reported that he, like his American colleague, remains because of his recipients' transformations and joy (Yasuoka, 2019). This anecdote reveals that although the United States conducts the greatest number of transplants each year, the emotions associated with this position may be independent of nationality. The effort of surgeons to refocus the recovery procedures on the recipients may also be one reason why donor families feel silenced by the transplant system once procurement is complete (Sharp, 2001).

Unlike heart transplants, liver and kidney transplants can be donated by living donors, and given the low rate of brain dead donation in Japan, this option is relied upon more frequently than in the United States (Yasuoka, 2019). Liver and kidney specialists have a more positive view of brain dead donation and procurement than heart surgeons: "I think that organ donation from a dead person is a wonderful thing" (Yasuoka, 2019, p. 32), and, "The 'gift of life,' how should I say...is one of the behavioral principles that makes the world turn" (Yasuoka, 2019, p.34). However, this dedication to recipients also challenges them. A kidney transplant surgeon mentioned difficulties staying objective, especially when performing children's transplants, "is a very difficult thing to do"

(Yasuoka, 2019, p. 36). Liver and kidney transplant surgeons have specific concerns about procuring from healthy living donors given the potential for harm (Yasuoka, 2019). This concern may explain the less troubled views of procurement from brain dead donors by kidney and liver surgeons in comparison to heart transplant surgeons.

The second involved party in transplantation are recipient and donor coordinators. These individuals work separately at each end of the transplantation process. Recipient coordinators support recipients before and after their transplant, physically and mentally (Yasuoka, 2019). Donor coordinators approach donor families to obtain consent and maintain the stability of each donor preceding procurement (Sharp, 2001; Yasuoka, 2019). In a recent study, recipient coordinators expressed similar views of transplantation when describing children being revitalized by their new organs (Yasuoka, 2019). Additionally, they expressed similar concerns of liver and kidney surgeons regarding living organ donation. However, unlike surgeons who feared potentially harming a healthy donor, recipient coordinators' fears focused on family tension and relationship fallout between living donor candidates and waiting transplant patients, as one coordinator noted, "I don't think living transplantation is a good thing like organ donation" (Yasuoka, 2019, p. 38). This pressure on living donors by an ailing family member may be heightened in Japan due to a lower volume of brain dead donation procedures, but also by a "technological imperative."

The success of transplantation transformed a once experimental and risky procedure into standard practice, and standard practice created an expectation to prolong life and receive a new organ (Kaufman, 2006). Specifically focusing on living kidney donation, Kaufman (2006, p. 3) recognizes the loss of choice in this process that leads to

“the perceived impossibility of saying no” to life-extending interventions. Additionally, there is intense pressure on family members, particularly adult children, to donate (Kaufman, 2006). The normalization and naturalization of older kidney recipients, who increasingly rely on living donors, consequently normalizes and naturalizes the denial of our inevitable deaths (Kaufman, 2006). Kaufman’s conclusions are recognized by a Japanese recipient coordinator. She notes that organ transplantation provides an opportunity to think about death, a topic not discussed while growing up in Japan (Yasuoka, 2019). However, the coordinator then explains, “Suddenly, when told ‘Let’s think about death,’ we can’t think about it” (Yasuoka, 2019, p.38). The international denial of death speaks to the influence of biomedicine in our society that is often not realized by the nurses, doctors, donors, or recipients involved.

The third involved party in transplantation are recipients. Recipient happiness, health, and appreciation are direct evidence of transplantation’s success and are frequently promoted by organ procurement organizations to promote donation (citation?). Many recipient narratives reflect these emotions, but some narratives uncover the problematic conceptual framework reinforced by the transplant system and individual cultural and political contexts ((Kierans, 2011; Yasuoka, 2019). A shared emotion of all the recipients interviewed by Yasuoka (2019) was gratitude toward the donor family. However, gratitude was quickly mixed with other feelings of guilt toward the donor and donor family, knowing an individual died allowing them to live (Yasuoka, 2019). As a result, many recipients attempted to offer reciprocation for the donated organ to the donor’s family (Yasuoka, 2019). The Japanese gift exchange tradition conducted twice a year, may contribute to the obligated sense to reciprocate gifts; it may also influence the

low donation rates within Japan as there is often no way to reciprocate a non-material gift such as a life-sustaining organ (Yasuoka, 2019).

Regardless of the cultural forces affecting decisions and feelings, each recipient had unique experiences based on the unique circumstances of each transplant. One recipient of a simultaneous pancreas and kidney transplant expressed overwhelming positive emotions and praise to the donor, donor family, and doctors. This expression was influenced by his critical condition before his transplant, “I don’t have to be overcome with terror of a hypoglycemic attack anymore” (Yasuoka, 2019, p. 55). Despite the renewed lease on life, this recipient only told his parents about his transplant out of fear of being shamed or accused of cannibalism by conservative members of his family and community (Yasuoka, 2019). One traumatic experience left another recipient with survivor’s guilt. At the age of fourteen, this recipient was sent abroad to Australia among eight other children suffering mild to critical liver failure. She received a new liver from a brain dead donor and was the only one out of the eight other kids she met in the hospital waiting room to survive. Paradoxically, she describes she had the mildest symptoms but the highest chance of survival which is why doctors chose her as the recipient (Yasuoka, 2019). Relating to this experience, another recipient mentions transplantation trades physical pain for psychological pain, and that “organ transplantation is a medical treatment that requires mental toughness” (Yasuoka, 2019, p. 58).

Given the increased reliance of international brain dead donors by Japanese recipients, we cannot ignore the legitimate concern, specifically addressed by Black communities, that their donated organs go to someone in their community (Williamson et al., 2017). Yasuoka (2019) notes that American hospital systems accept 5 percent of their

patients from countries with low healthcare provisions, but also that this 5 percent can be entirely Japanese in some cases. The international sharing of organs is mainly supported by the advancement of immunosuppressant therapy which reduces the reliance on genetic matching (Kierans, 2011). However, this advancement is consequential for the world's most vulnerable populations (Kierans, 2011). Cyclosporine, the ubiquitous immunosuppressant drug, may contribute to vulnerable communities in the U.S. rarely reaping the benefits of transplantation within their community, perpetuating medical mistrust. This circumstance is recognized by Japanese recipients who are often hesitant to disclose their nationality in thank you notes to donor kin (Yasuoka, 2019).

The narratives of Japanese recipients reflect similar sentiments from medical anthropologist Kierans (2011, p. 1473) who noted, "Transplantation does extend life, but the lives so extended are radically altered in the process." Kierans (2011) critically remarks that the immunosuppressant therapy that is essential for a successful transplant has many consequences on recipient health and wellbeing. She also notes that the transplant system itself positions recipients as "beneficiaries of medical technologies" (Kierans, 2011, p. 1470), and further that recipient suffering is downplayed as donor kin suffering is simultaneously elevated. Daily immunosuppressants often cause devastating and unforeseen side effects for recipients which can include weight gain, excess bodily hair, and increased susceptibility to viruses and infections (Kierans, 2011). Renal recipients in Mexico expecting to resume a normal healthy life instead face the side effects of daily immunosuppressants and often may not be healthy enough to return to work (Crowley-Matoka, 2005). Additionally, Irish transplant recipients note mental and physical affects of immunosuppression including difficulties with continued sickness,

forming relationships, and maintaining a regular working life (Kierans, 2005). The difference between expectation and reality for recipients is created by the transplant system which promotes a collective narrative of recipients centered around the “gift of life” (Kierans, 2011). Specific to living transplants where the donor may personally know the recipient, there is often an unspoken expectation on recipients to be good stewards of the donated organ and pressure to be well when one is not (Kierans, 2011). Thus some recipients disengage with family and friends, who no longer view them as patients, to alleviate some of the effects of recipiency (Kierans, 2011).

The last involved party to discuss are donor kin. Donor kin are the family members who decide whether to donate or not in the absence of first person consent, granted at the time of registration. In the presence of first person consent documentation, donor kin will often be asked to grant the wishes of the deceased, alleviating this decision to donate or not from immediate family members. Narrative data supports the finding from quantitative literature that the strongest familial authorization rates occur when the donor is registered (Shah et al., 2018; Yasuoka, 2019). When families make donation decision without knowing the wishes of the donor, it is important to allow family members to discuss among themselves and make this decision freely, because feeling coerced or pressured in this decision often increases the intensity and length of the grieving process (Yasuoka, 2019). Coercion also contributes to mistrust toward medical professionals and the donation process. Pressure and coercion from donor coordinators in the US may be intrinsic to the system. Sharp (2001) mentions that procurement professional themselves endure pressure from superiors who may implement unofficial monthly donor quotas. In one case, the pressure from coordinator superiors led some to

offer to cover burial costs to persuade hesitant donor families (Sharp, 2001).

The narrative of a Japanese father who chose to donate his twenty-one year old daughter's organs without her preexisting agreement to donate illustrates this finding. The donor father agreed to donation "unquestionably" when it was mentioned by his daughter's doctor, but without the full consideration of his family's opinions, Twelve years after the decision he reported feeling guilt and regret (Yasuoka, 2019). Pressure in this scenario may be tied to the paternalistic relationship between doctor and patient, but as this dynamic changes in Japan, more attention should be paid to the techniques doctors and donor coordinators use to persuade family members.

Even if an individual registers, it is still important for family members to explicitly discuss their wishes with each other to prevent negative personal experiences through this process. For an African-American mother approached by doctors who disclosed her son's donor registry, she worried if he still wanted to donate at the time of his death. Her hesitation to support the decision created a sour experience which left her feeling very disrespected by medical professionals (Williamson et al., 2017). Only her son's corneal tissue was viable for procurement by the time these issues were resolved (Williamson et al., 2017).

In addition to the way medical professionals shape donor family narratives, Yasuoka (2019) also explains that a mother's reaction to donating her child's organs may be more intense than other family members. This phenomenon is partly due to Japanese culture which creates a much stronger relationship between mother and child, and may be due to the experience of childbirth (Yasuoka, 2019). One Japanese mother's story reveals

the emotional intensity of crying in an Australian nurse's arms and realizing "Australian and Japanese mothers are the same" (Yasuoka, 2019). The emotional intensity faced by this mother morphed into feelings of isolation without any chance to communicate with her son's organ recipients which highlights the need for mental healthcare for donor families (Yasuoka, 2019). Long-term mental health care for donor families is also supported by Sharp's (2001) data revealing that the process of donation, especially after a traumatic death, may actually prolong or intensify mourning. Donation may actually make closure an impossibility, despite the claims by OPOs believing it will speed up the mourning process and lessen grief (Sharp, 2001).

Along with the unreliable claims of OPOs regarding donor kin emotions, there is a more deliberate professional repression of donor kin by OPOs. Donor families in the US often feel silenced and ignored by OPOs (Sharp, 2001). OPOs view donor kin as volatile and dangerous, potentially expressing their grief or sharing the traumatic or violent nature of the donor's death (Sharp, 2001). This concern by OPOs is a problem created by themselves; donor coordinators purposefully mask the violent nature of the donor's death from conversation, instead only promoting life despite both sides, life and death, being inextricably linked in the process (Sharp, 2001). Life is situated at the center of transplantation through ecological metaphors like trees, flowers, vegetables, and birds as powerful symbols of life (Sharp, 2001). This promotional material that uses these metaphors invites open abhorrence from donor kin, because it deliberately ignores the grief and painful end-of-life decisions family members face after losing a loved one (Sharp, 2001).

Green imagery, particularly "donor gardens" depersonalizes donors long after

procurement. Donors are still objectified; trees and rose bushes purposefully do not have names. However, donor kin have defied the system attempting to silence them through donor quilts and virtual donor ceremonies (Sharp, 2001). Online memorials remove censorship and scripts that OPOs strictly enforce. Family members can share their darkest thoughts and struggles with their loss and the transplant process, bringing some peace in the process.

Reviewing the different narratives of surgeons, coordinators, recipients, and donor families adds new perspective in understanding organ donation and transplantation. Surgeons and coordinators reveal the difficulties of working in a technologically advanced, yet relatively young, field. Their narratives reveal some of the ethical dilemmas that the globalized system of transplantation faces, particularly regarding living transplantation. Recipient narratives illustrate immense feelings of gratitude, but also the untold aftereffects of life with a transplanted organ. Donor kin narratives share a largely ignored and silenced perspective throughout the whole process. These narratives, practically non-existent in quantitative literature, highlight the ethically-fraught problems created by the system itself and give voice to the statistically significant finding of quantitative surveys. These narratives also prove the interconnected nature of each party, all connected to the donor. Organ procurement organizations share only the benefits of donation and transplantation, and this sentiment is perpetuated by biomedical research and professionals. However, understanding the concerns of each involved party can strengthen the system as a whole; to ignore any party in this process may only hurt the goals of donation and transplantation from the inside out.

VII. SHORTCOMINGS, LIMITATIONS, AND FUTURE DIRECTIONS

This thesis initially began by exploring the factors involved in facilitating or impeding individuals' decisions to register as organ donors, yet this examination exposed some of the shortcomings and limitations of the organ donation and transplantation process. Some might question if organ transplantation is justifiable, given its ethically fraught nature is largely veiled by national transplant organizations. This line of thinking is misleading though because organ transplantation as a whole saves lives. In fact, thousands of lives are transformed each year through transplantation. The most important aspect in assessing transplantation's complications is maintaining a balance between positive outcomes and negative consequences. This last section addresses the most salient issues of studying and increasing donation rates and then outlines potential solutions.

As each section has illustrated, quantitative and qualitative literature both provide important perspectives on the attitudes and behaviors of the transplantation process. However, quantitative and qualitative research are rarely conducted in tandem with each other and rarely cite each other. This is problematic because only focusing on one side of the literature blocks a comprehensive view of the system to understand what shapes behavior and ultimately donation rates. A holistic perspective is particularly useful within transplantation as people are the main focus of the process; understanding these unique human experiences guided by quantitative analysis can produce statically significant data with a voice. The richest conclusions are made when combining these literatures because it exposes the complex web of attitudes, behaviors, and influences that affect donation.

Analyzing how donation and transplantation are studied reveals the problematic

nature of the Health Belief Model (HBM). The HBM's theoretical framework positioned education and knowledge of transplantation as the deciding factor to donate, despite clear evidence that this decision involves multiple factors. The HBM frames both quantitative and qualitative literature, but is futile in truly understanding the barriers to donation. By singularly viewing donation rates as an education problem, researchers in both fields downplay the other factors dictating donation decisions. In qualitative studies, potential barriers were discussed in depth, yet the proposed solution to these problems (some which were historically and systemically based) was simply to improve promotional materials. Qualitative focus groups do have potential to add perspective and even challenge education's value as presented by the HBM. In fact, Williamson et al.'s (2017) study illustrating medical mistrust within the African-American community does challenge education's value in decision making, but the HBM's influence over these valuable perspectives only finds increasing education as the solution. As long as the HBM's framework continues to influence research in this field, the full scope of influences on potential donors cannot be explored.

One of the perceived barriers identified following the HBM framework is medical mistrust. Medical systems including transplantation have systematically and historically worked against minority communities. Although OPOs cannot change past events, they can recognize their contributing part in perpetuating mistrust. Recommendations could involve reviewing the criteria that puts patients on the transplant list in an attempt to reduce demand and lessen the burden on the public. However, this may be challenging given the forward direction and momentum of transplantation technology as it becomes standard practice. An alternative option to reduce demand would be for OPOs to partner

with various health initiatives to prevent kidney, liver, and other preventable organ diseases that increases the demand of organs. Promoting healthy living habits in hopes of reducing the pressure on the public to donate may also transform the image of OPOs from being “vultures” and may improve trust among the community.

In Donate Life America’s 2021 Annual Report, the organization has a page on diversity and inclusion and does report that they have promoted healthy living in multiethnic communities to reduce the need for transplants (Donate Life America, 2021). However, this initiative is primarily disseminated through social media. More needs to be done at the ground level by these organizations to promote healthy living in these communities. OPOs could also contact community leaders to host monthly picnics or potlucks to connect with the community, and connect the community itself, while sharing healthy habits. Interestingly, OPOs do recognize the need to reach out to local leaders and influences in the community. The 2021 Annual Report discusses a collaboration with streetwear designers and brands to reach the community that way (Donate Life America, 2021).

On top of these recommendations and Donate Life America’s ongoing efforts, the organization can further impact these communities by increasing their social capital which drives voluntary and altruistic behavior (Ladin et al., 2015). Increased social capital increases prosocial behavior, and living in areas with less crime, less residential segregation, more social cohesion, and greater political participation, increases prosocial behavior (Ladin et al., 2015). Out of these variables, it seems most reasonable for OPOs to invest in communities to increase social cohesion as they often frame organ donation as a moral imperative (Kierans & Cooper, 2011). Increasing social cohesion might

include hosting monthly community events, and investing in the restoration or construction of community spaces like libraries or activity centers. Again, investing directly in communities will also transform OPOs image among skeptical communities and increase trust.

One of the ominous uncertainties of transplantation is the technical imperative that complicates living donation and drives biomedicine's cultural force. As coordinator narratives detail, our collective denial of death transforms the view of our bodies. Biomedicine dictates that our bodies are machines with replaceable parts. This idea is a treacherous path to follow because it quickly leads to ideas of immortality. Transplant leaders must recognize the biomedical worldview they operate under and define boundaries for the system to balance the benefits against negative consequences, specifically those of living donation. Additionally, thoroughly understanding biomedicine's influence in the field allows transplantation leaders to foster understanding and respect among other communities and cultures to find common ground as humans in a technologically advanced world. The field of transplantation is culturally situated and fraught, thus respect for others' decisions, regardless the reasoning, should remain a top priority for transplant professionals to maintain healthy relationship with the community and allow the system to flourish.

VII. CONCLUSION

This thesis identified several factors influencing decision-making of registering as an organ donor. Through a literature review, the differences between quantitative and qualitative data were considered. Education is often at the forefront of donation conversations. However, most people understand the need and benefits of organ donation and still choose not to donate; other factors exist. These factors are often overlooked by the Health Belief Model, the primary conceptual framework that guides both literatures. Religion can be beneficial to increasing donation rates because it connects local leaders with the community. Although the nuances of different religions and individual interpretations of religion may persist beyond the formal acceptance within major religions. Altruistic motivations are the biggest benefit to donation, but this factor is further influenced by community-level variables according to the social capital theory. Medical distrust is a particularly strong barrier to donation that is shaped by a history working against minority communities, those with the lowest donation rates. Narratives reveal a dimension of the innerworkings of the transplant system that is not seen by potential donors yet heavily shapes the system and potential donor attitudes. With all these factors in mind, transplant leaders have an important role to address the hesitation of many potential donors through a more holistic approach to their field. Understanding the complexities and untangling transplantation's web of involved parties helps these professionals better the experiences of everyone involved.

LITERATURE CITED

- Arghode, V. (2012). Qualitative and Quantitative Research: Paradigmatic Differences. *Global Education Journal*, 2012(4), 155–163.
- Boulware, L. E., Troll, M. U., Wang, N. Y., & Powe, N. R. (2006). Public Attitudes Toward Incentives for Organ Donation: A National Study of Different Racial/Ethnic and Income Groups. *American Journal of Transplantation*, 6(11), 2774–2785. <https://doi.org/10.1111/j.1600-6143.2006.01532.x>
- Champion, V. L., & Skinner, C. S. (2008). The health belief model. In K. Glanz, B. K., Rimer, K. Viswanath (Eds.), *Health Behavior and Health Education: Theory, research, and practice* (4th ed., 45-66). Jossey Bass.
- Crowley-Matoka, M. (2005). Desperately seeking “normal”: the promise and perils of living with kidney transplantation. *Social Science & Medicine*, 61(4), 821–831. <https://doi-org.libproxy.txstate.edu/10.1016/j.socscimed.2004.08.043>
- Donate Life America (2021). *2021 Annual Update*. <https://www.donatelife.net/wp-content/uploads/2021/09/2021DonateLifeAmericaAnnualUpdate.pdf>
- Gillman J. (1999). Religious perspectives on organ donation. *Critical Care Nursing Quarterly*, 22(3), 19–29. <https://doi-org.libproxy.txstate.edu/10.1097/00002727-199911000-00005>
- Gallagher, C. (1996). Religious Attitudes regarding Organ Donation. *Journal of Transplant Coordination*, 6(4), 186–190. <https://doi.org/10.1177/090591999600600407>
- Güden, E., Çetinkaya, F., & Naçar, M. (2013). Attitudes and Behaviors Regarding Organ Donation: A Study on Officials of Religion in Turkey. *Journal of Religion and Health*, 52(2), 439–449. <https://doi.org/10.1007/s10943-011-9490-8>
- Health Resources & Services Administration. (2021, October). Organ donation statistics. <https://www.organdonor.gov/learn/organ-donation-statistics>
- Hodge, F., Bellanger, P., & Norman, C. (2011). Organ Donation and Transplantation. *American Indian Culture and Research Journal*, 35(3), 79–90. <https://doi.org/10.17953/aicr.35.3.b2035853561111k5>
- Holman, A. (1,2). (n.d.). Religion and the body an overview of the insertions of religion in the empirical psycho-social research lines on the body. *European Journal of Science and Theology*, 8(3), 127–134.
- Kierans, C. (2011). Anthropology, organ transplantation and the immune system: Resituating commodity and gift exchange. *Social Science & Medicine*, 73(10), 1469–1476. <https://doi.org/10.1016/j.socscimed.2011.09.008>

- Kierans, C., & Cooper, J. (2011). Organ donation, genetics, race and culture: The making of a medical problem (Respond to this article at <http://www.therai.org.uk/at/debate>). *Anthropology Today*, 27(6), 11–14. <https://doi.org/10.1111/j.1467-8322.2011.00837.x>
- Ladin, K., Wang, R., Fleishman, A., Boger, M., & Rodrigue, J. R. (2015). Does Social Capital Explain Community-Level Differences in Organ Donor Designation?: Social Capital and Community Differences in Organ Donor Designation. *Milbank Quarterly*, 93(3), 609–641. <https://doi.org/10.1111/1468-0009.12139>
- Li, A. H.-T., Rosenblum, A. M., Nevis, I. F., & Garg, A. X. (2013). Adolescent classroom education on knowledge and attitudes about deceased organ donation: A systematic review. *Pediatric Transplantation*, 17(2), 119–128. <https://doi.org/10.1111/petr.12045>
- Pauli, J., Basso, K., & Ruffatto, J. (2017). The influence of beliefs on organ donation intention. *International Journal of Pharmaceutical and Healthcare Marketing*, 11(3), 291–308. <https://doi.org/10.1108/IJPHM-08-2016-0040>
- Quick, B. L., LaVoie, N. R., Scott, A. M., Bosch, D., & Morgan, S. E. (2012). Perceptions About Organ Donation Among African American, Hispanic, and White High School Students. *Qualitative Health Research*, 22(7), 921–933. <https://doi.org/10.1177/1049732312439631>
- Radecki, C. M., & Jaccard, J. (1997). Psychological aspects of organ donation: A critical review and synthesis of individual and next-of-kin donation decisions. *Health Psychology*, 16(2), 183–195. <https://doi.org/10.1037/0278-6133.16.2.183>
- Rumsey, S., Hurford, D. P., & Cole, A. K. (2003). Influence of knowledge and religiousness on attitudes toward organ donation. *Transplantation Proceedings*, 35(8), 2845–2850. <https://doi.org/10.1016/j.transproceed.2003.10.078>
- Shah, M. B., Vilchez, V., Goble, A., Daily, M. F., Berger, J. C., Gedaly, R., & DuBay, D. A. (2018). Socioeconomic factors as predictors of organ donation. *Journal of Surgical Research*, 221, 88–94. <https://doi.org/10.1016/j.jss.2017.08.020>
- Sharp, L. A. (2001). Commodified Kin: Death, Mourning, and Competing Claims on the Bodies of Organ Donors in the United States. *American Anthropologist*, 103(1), 112–133. <https://doi.org/10.1525/aa.2001.103.1.112>
- Sharp, L. A. (2006). *Strange harvest: Organ transplants, denatured bodies, and the transformed self*. University of California Press.
- Tarabeih, M., Abu-Rakia, R., Bokek-Cohen, Y., & Azuri, P. (2020). Christianity, Islam, Judaism, and unwillingness to donate organs post-mortem. *Death Studies*, 1–8. <https://doi.org/10.1080/07481187.2020.1734114>

- Traino, H. M., & Siminoff, L. A. (2013). Attitudes and acceptance of First Person Authorization: A national comparison of donor and nondonor families. *Journal of Trauma and Acute Care Surgery*, 74(1), 294–300.
<https://doi.org/10.1097/TA.0b013e318270dafc>
- Wakefield, C. E., Watts, K. J., Homewood, J., Meiser, B., & Siminoff, L. A. (2010). Attitudes toward Organ Donation and Donor Behavior: A Review of the International Literature. *Progress in Transplantation*, 20(4), 380–391.
<https://doi.org/10.1177/152692481002000412>
- Washington, H. A. (2006). *Medical apartheid: The dark history of medical experimentation on Black Americans from colonial times to the present* (1st ed). Doubleday.
- Wilczek-Rużyczka, E., Milaniak, I., Przybyłowski, P., Wierzbicki, K., & Sadowski, J. (2014). Influence of Empathy, Beliefs, Attitudes, and Demographic Variables on Willingness to Donate Organs. *Transplantation Proceedings*, 46(8), 2505–2508.
<https://doi.org/10.1016/j.transproceed.2014.09.024>
- Williamson, L. D., Reynolds-Tylus, T., Quick, B. L., & Shuck, M. (2017). African-Americans’ perceptions of organ donation: ‘Simply boils down to mistrust!’ *Journal of Applied Communication Research*, 45(2), 199–217.
<https://doi.org/10.1080/00909882.2017.1288293>
- Williamson, L. D., Bigman, C. A., & Quick, B. L. (2019). A Qualitative Examination of African Americans’ Organ Donation-Related Medical Mistrust Beliefs. *Howard Journal of Communications*, 30(5), 430–445.
<https://doi.org/10.1080/10646175.2018.1512064>
- Yasuoka, M.-K. (2019). *Organ donation in Japan: A medical anthropological study*.
- Zink, S., Zeehandelaar, R., & Wertlieb, S. (2005). Presumed vs Expressed Consent in the US and Internationally. *AMA Journal of Ethics*, 7(9), 610-614.