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Exploring Discussions and Communication About Organ Donation Among Minority Family Members

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Abstract

Exploring Discussions and Communication About Organ Donation Among Minority Family Members

By Mary E. Davis

Problem/Background: Organ transplantation for patients with end-stage organ failure is a medical procedure that replaces failing organs with healthier organs. Preceding the technique of organ transplantation, organ failure patients had very few choices for treatment. Voluntary altruistic acts of organ donors are the source for most organs recovered for transplant. Failure in family discussion of death planning has contributed to many lost opportunities at saving lives that can only be achieved by donor or family consent. This lack of discussion among minority family members of potential organ donors has created major barriers regarding organ donation. Consequently, the growing shortage of organs has resulted in 22 people per day dying in the United States while waiting for organ transplants.

Key Aims: The purpose of this study was to use secondary data to explore how individuals develop willingness and attitudes to become organ donors. Secondly, how do these individuals overcome barriers and feel comfortable enough to register for organ donation. Lastly, this study explored the various ways families acquire the willingness to register through healthy conversations that promote organ donation.

Methods: A total of 85 peer reviewed articles with 12 core articles regarding the subject of communication and discussion were included in this systematic literature review. The aim of this study was to explore willingness and attitudes toward communication and discussion between family members regarding organ donation among minority populations.

Conclusion: The connection between attitude, willingness, awareness and knowledge were very important in bringing individuals from stages of negativity toward points of willingness to be organ donors. It also showed how critical educational interventions are to overcoming this critical issue. Revisiting all barriers and creating more interventions and in-depth educational programs is necessary for minority families to understand the effects of behaviors and attitudes toward organ donation.

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Chapter 1 - Introduction

Background

Organ transplantation is one of the greatest medical advances in the history of medicine (Karamehic et al., 2008). Organ failure patients now have the opportunity to not only extend their lives, but also enjoy a better quality of life. Transplantation replaces failing organs with healthier organs predominantly from altruistic deceased donors. However, kidney and liver transplants are also possible through living donations.

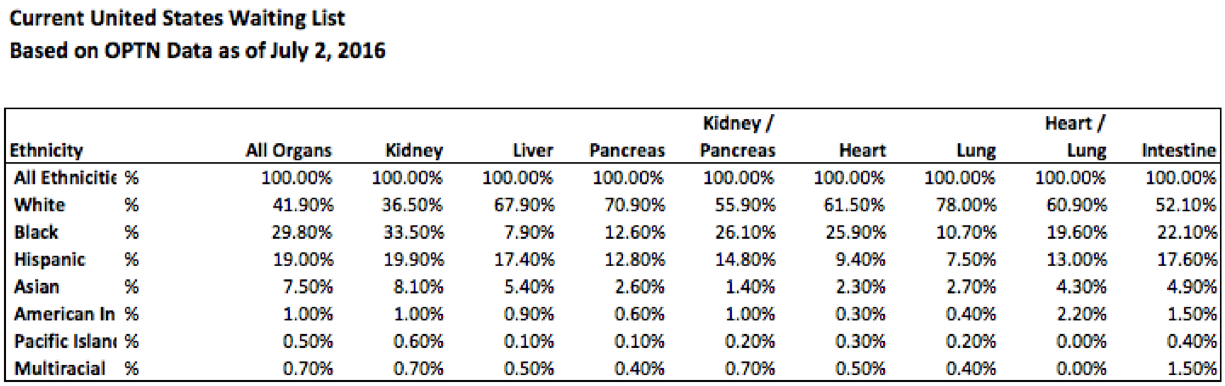
The advancement of immunosuppressant drugs that prevent rejection of transplanted organs has enhanced transplantation, making it is the option of choice for most patients and families dealing with organ failure (L. A. Siminoff, Gordon, Hewlett, & Arnold, 2001). However, the waitlist of patients waiting for organs has been growing at an exponential rate every year since the program inception (OPTN, 2016b; SRTR.org, 2016). Oddly enough, the successes of transplantation have created more of a gap in supplying the amount of organs needed for patients with organ failure. The human component (organ donation) of making transplantation work has proven there are very few clear answers of how to resolve organ shortages. Consequently, an increase in organ procurement is very important for all society.

Approximately 22 people die daily while waiting for organ replacement in the United States (US). Currently there are over 120,000 patients on the national registry waiting to receive an organ replacement; 80% of these individuals are waiting to receive kidneys. The breakdown by ethnicity as of April 2016 are as follows: Caucasians - 42.1%, African American - 29.9%, and Hispanics - 18.5%; all others are less than 10% as stated by Organ Procurement Transplantation Network (OPTN) (OPTN, 2016b; SRTR.org, 2016).

Donor shortages are a significant problem throughout the US. Shortages exist in all populations, but there are significant disparities in minority populations (Boulware et al., 2002; DeJong et al., 1998; Fahrenwald, Belitz, & Keckler, 2010; Purnell et al., 2011). Many minority populations have similar and somewhat specific factors that must be addressed to improve organ donation at the end-of-life. Additionally, disparities exist among specific populations that must be addressed in order for organ donation to be accessible for all individuals who suffer from organ failure.

The gap between supply of eligible organs and demand is growing larger every year as documented by UNOs and summarized in Table 1. Minority requests for transplant is even more alarming and attributable to the prevalence of organ failure. African Americans and Hispanics are almost 50% of the waiting list, despite only being 13% and 17% of the population.

Table 1. United States Waiting List for Solid Organs



Current United States Waiting List
Based on OPTN Data as of July 2, 2016

Ethnicity		All Organs	Kidney	Liver	Pancreas	Kidney / Pancreas	Heart	Lung	Heart / Lung	Intestine
All Ethniciti	%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%
White	%	41.90%	36.50%	67.90%	70.90%	55.90%	61.50%	78.00%	60.90%	52.10%
Black	%	29.80%	33.50%	7.90%	12.60%	26.10%	25.90%	10.70%	19.60%	22.10%
Hispanic	%	19.00%	19.90%	17.40%	12.80%	14.80%	9.40%	7.50%	13.00%	17.60%
Asian	%	7.50%	8.10%	5.40%	2.60%	1.40%	2.30%	2.70%	4.30%	4.90%
American In	%	1.00%	1.00%	0.90%	0.60%	1.00%	0.30%	0.40%	2.20%	1.50%
Pacific Islan	%	0.50%	0.60%	0.10%	0.10%	0.20%	0.30%	0.20%	0.00%	0.40%
Multiracial	%	0.70%	0.70%	0.50%	0.40%	0.70%	0.50%	0.40%	0.00%	1.50%

www.organdonor.gov

It should be noted that this paper will cover only solid deceased donor organ donation. Additionally, individuals of African descent will be referred to as African Americans with the acknowledgement that the population consists of other African lineage.

Link Between Family Communication and the Organ Shortage

Only 40% of the American population has registered to be organ donors, as stated by Donate Life America in 2012. Of this 40%, many of the opportunities for transplant are lost with the largest barrier being family members overriding donor designations of their loved ones after death. The most common reasons given were that families never had conversations or an understanding from donors of their wishes to donate (Sadler & Sadler, 2015).

Determinants of Organ Failure in Minority Populations

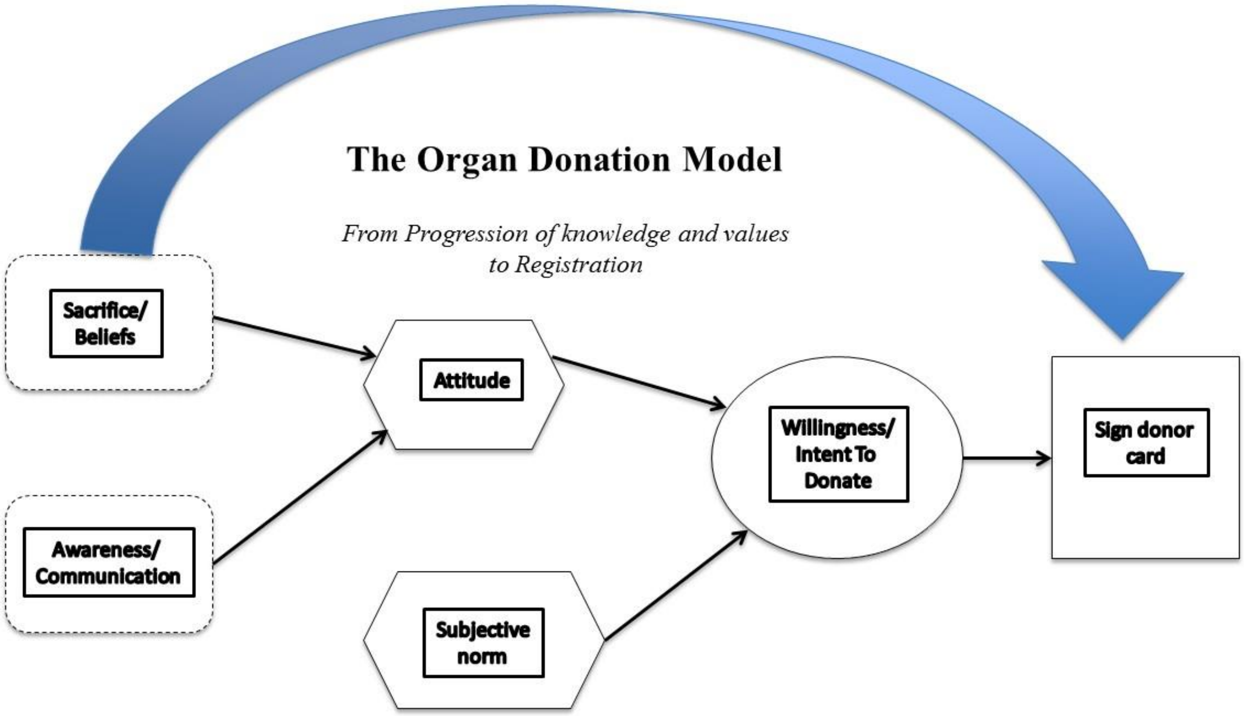
Minorities are disproportionately represented among individuals with organ failure as well as those on the waiting list. African Americans and American Indians are at higher risk of End-Stage Renal Disease (ESRD) than other minorities due to tendencies of diabetes. African Americans are also at a higher risk of hypertension, which puts them at an even higher risk of kidney failure (Joint Commission, 2004). This disparity is highly noteworthy in reference to shortages and waitlist for kidneys in African American populations. African Americans represent 30% of the waitlist for kidneys, despite being only 13% of the population in the US (OPTN, 2016a).

As mentioned previously, the prevalence of diabetes and hypertension leads many patients to end-stage organ failure. Despite this fact, African Americans are hesitant about designating for donation (S.E. Morgan, 2004). This twofold problem has resulted in organ shortages, disproportionally affecting African Americans in almost all areas throughout the US. African Americans are in much higher demand for organs than many ethnicities, which results in more time on the waiting list and eventually more deaths among African Americans. Secondly, while transplantation has no specific racial/ethnic criteria toward race as far as recipients are concerned, outcomes are improved when ethnicities are matched. Blood types and human leukocyte antigens differ somewhat by ethnicity, therefore compatibility with other ethnicities may be a weaker match when deciding who receives a donated organ (Mauch & Bratton, 2014).

Theoretical Framework - The Organ Donation Model (ODM)

The Organ Donation Model (ODM) provided the theoretical framework for this Systematic Review. ODM was developed by S.E. Morgan (2006), with the addition of ‘attitude’ and ‘social components’. ODM is influenced by the Theory of Reasoned Action (TRA) and revised from previous research by (Horton & Horton), as a guiding framework. ODM identifies the impact of willingness and the effects of having discussions about organ donation with next of kin and loved ones, when combined with TRA. It shows how attitudes of self, next of kin, and loved ones assist in shaping the decision of donation. It also highlights the influence of culture and spiritual values, and its effect on organ donation as displayed in Figure 1.

Figure 1. The Organ Donation Model



(S.E. Morgan, 2006)

Purpose Statement

The purpose of this study was to use secondary data to explore how individuals develop willingness and attitudes to become organ donors. Secondly, how do these individuals overcome barriers and feel comfortable enough to register for organ donation. Lastly, this study will explore the various ways families acquire the willingness to register through healthy conversations that promote organ donation.

Research Questions

In the last 20 years between 1996 and 2006, a breakdown in communication has occurred among minorities in doing proper death planning in regards to organ donation. What factors influence the act of family communication concerning discussion of organ designation? Can family communication between members help in improving outcomes of organ procurement?

Significance Statement

The organ donation process utilized in the US is an opt-in altruistic system that is dependent on all individuals to participate. The system's success is dependent on the understanding that any individual could possibly be an organ donor or an organ recipient. All individuals are stakeholders with a common purpose in making the system work through fairness, trust and cooperation. Individuals become organ donors by registering their names with UNOS. If these individuals should die in a state of brain death, cardiac death, or their families donate posthumously; UNOS will match donor organs with organ failure patients who need transplants.

Shortages in organ procurement due to lack of participation by all eligible individuals and ethnicities across the US has created a public health concern. Identifying barriers and creating interventions that work is of high importance in reducing mortality rates. Key elements such as next of kin and loved ones of the deceased can create serious repercussions when terminating the process of transplantation simply by declining patient's designation to be organ donors. Health Care Provider (HCPs) and Organ Procurement Organization (OPOs) are often caught in awkward situations when families are asked to be benevolent while they are grieving the death of a loved one and possible donor.

The opportunity for procurement may be lost if deceased organ donors failed to have a discussion with their families or loved ones. Families make decisions based on what they feel is correct in moments of anguish if discussion and decisions were not made before death. This discussion is necessary for next of kin to be knowledgeable about the desires of the potential donor.

Definition of Terms

The following phrases and terms are used throughout the document and associated with organ donation, organ donation procedures, and policies related to organ donation and procurement.

Altruism - Altruism is the unselfish desire for the welfare of others. In regards to low supply of organ and tissue donation this specifically applies to the objective of improving the lives of patients who are the impending recipients of donated organs (Institute of Medicine, 2006)

Antibody - A protein substance made by the body's immune system to attack a foreign substance, for example, a blood transfusion, virus or pregnancy. Because antibodies attack transplanted organs, transplant patients must take powerful drugs to reduce the body's attack on the transplanted organ. See anti-rejection medicine. (organdonor.gov)

Brain Death – Irreversible loss of all brain function. The largest source of transplantable organs used for transplant to patients with organ failure (L. A. Siminoff, Gordon, et al., 2001).

Candidate - A patient who has been placed on the National Waiting List for solid organ transplantation.

Dialysis - A mechanical process designed to remove toxic substances from the blood, including correcting the balance of fluids and chemicals in the body and removing wastes when the kidneys are unable to do so. See hemodialysis and peritoneal dialysis. (organdonor.gov)

Sudden Cardiac Death - Unexpected death due to cardiac causes that occurs in a short time period (generally within 1 hour of symptom onset) in a person with known or unknown cardiac disease.

Coma – a state of prolonged unconsciousness that can be caused by a variety of problems — traumatic head injury, stroke, brain tumor, drug or alcohol intoxication, or even an underlying illness, such as diabetes or an infection. (www.mayoclinic.org)

Donor Designation—Documentation of an individual’s decision to donate organs, eyes, and/or tissues after death usually designated on a driver’s license or through a State donor registry. (organdonor.gov)

Donor Registry – A confidential database, which stores data from individuals registering to be organ donors. Most registries are contained separately by state by Organ Procurement Transplant Network OPTN. Data is input by OPTN staff and motor vehicle offices, and online portals. (organdonor.gov)

End-Stage Organ Disease—A disease that leads, ultimately, to permanent, complete failure of an organ to function. Some examples are emphysema (lungs), cardiomyopathy (heart), and polycystic kidney disease (kidneys). (organdonor.gov)

End-stage Renal Failure - The complete or almost complete failure of the kidneys to function. The kidneys can no longer remove wastes, concentrate urine, and regulate many other important body functions. (organdonor.gov)

First Person Consent/ Donor Designation - State laws ensuring legal authority to proceed with organ procurement without consent from the family based on a legal indication of the deceased's consent for donation, such as on a driver's license or other official document. (Organdonor.gov)

Donate Life America - Donate Life America manages and promotes the national brand for donation, Donate Life, and assists Donate Life State Teams and national partners in facilitating high-performing donor registries; developing and executing effective multi-media donor education programs; and motivating the American public to register now as organ, eye and tissue donors. (donatelife.net)

Immunosuppressant Drug - Chemical agents that cause the human body not to produce antibodies that normally fight off foreign material in the body. The production of these antibodies needs to be suppressed in order to permit the acceptance of a donor organ by the recipient's body. See also Anti-Rejection Medicine. (Organdonor.gov)

Persistent Vegetative State (PVS) - A vegetative state exists when a person is able to be awake, but is totally unaware. A person in a vegetative state can no longer “think,” reason, relate meaningfully with his/her environment, recognize the presence of loved ones, or “feel” emotions or discomfort. The higher levels of the brain are no longer functional. A vegetative state is called “persistent” if it lasts for more than four weeks. (americanhospice.org)

Sociodemographics – Sociological and demographic characteristics of a group or groups used for analysis in research.

Waiting list - A national database maintained by the OPTN of all patients waiting for an organ transplant. It is made up of sublists of patients waiting for specific organs. (organdonor.gov)

Acronyms

The following acronyms are used throughout the document and associated with organ donation and transplantation.

DCDD - Donation after circulatory determination of death

DHHS – Department of Health and Human Services

DLA – Donate Life America

FCC – Family Communication Coordinator

ESLD – End Stage Liver Disease

HCP – Health Care Provider

HRSA - Health Resources & Services Administration

HRSA/DoT - Health Resources and Services Administration, Division of Transplantation

NOTA - National Organ Transplant Act

OD – Organ Donation

OPO – Organ Procurement Organization

OPTN - Organ Procurement Transplant Network

PSDA - The Patient Self Determination Act

SCD – Sudden Cardiac Death

TBI – Traumatic Brain Injury

UAGA - Uniform Anatomical Gift Act

UNOS – United Network for Organ Sharing

Chapter 2 - Review of the Literature

A critical deficit of organ supply exist in minority populations as a result of low donor registrations (Joint Commission, 2004; Long et al., 2012; S.E. Morgan & Cannon, 2003; OPTN, 2016b). Disparities of demand versus a limited supply still exist, despite the numerous efforts by government agencies, organizations, etc. The rates of registration remain at low levels in spite of programs that promote the act of designating for donation (S.E. Morgan, 2004) (Roark, 1999).

The causes minorities decline donation are multifaceted in view of fundamental attitudes, beliefs and motivations based on experiences and culture in life (Mauch & Bratton, 2014). These attitudes, beliefs and motivations often create barriers in obtaining registrations and family consent (Siegel, 2009).

Barriers to Organ Donation

Organs must be recovered soon after brain or cardiac death of a donor in order for transplantation to occur. If there is no clarity of the donors wishes, then the decision is left for the next-of-kin/family to make the decision posthumously. When wishes of deceased donors are known, outcomes are improved because it enables donor families to make clear decisions and prevent hospitals and OPOs from having to ask the family for the donation in the midst of grief and confusion.

Although there have been incremental achievements over time, shortfalls still exist in changing attitudes and willingness toward organ donation among minorities populations. Many barriers toward minority organ donation can be firmly grounded in history or unsubstantiated viewpoints deeply rooted in individual acceptance (Long et al., 2012).

The growing concern over organ donation rates has continued to focus on barriers in minority communities, since these communities have the largest disparities and highest mortality rates regarding organ failure. Although barriers in minority communities are pronounced, they exist across all ethnic lines. Reducing major barriers between the community and the transplant process can assist in improving organ failure and survival rates in cultural ethnicities by increasing organ supply (Glazier, Heffernan, & Rodrigue, 2015; Siegel, 2009). The focus of this paper concentrated on barriers and factors leading to organ donation. This focus was specifically concerned with minority family attitudes and discussions toward organ donation.

Previous studies have revealed the fact that much of the documentation on reluctance to participate in the organ donation process is often research speculation with limited qualitative data (Long et al., 2012). Despite the possibility of flawed data, several researchers have listed very similar barriers that have obstructed organ donation over the past two decades (Irving et al., 2012) (Long et al., 2012) (S. E. Morgan, Miller, & Arasaratnam, 2002). Some common barriers include lack of knowledge about the organ donation process; religious beliefs; body integrity; relational ties; family influences; medical mistrust; validity of brain death; fear of early organ retrieval; and hesitations despite positive beliefs.

Lack of Knowledge about Organ Transplant and Donation

Lack of knowledge regarding organ donation and transplantation; distrust in the organ allocation system, and religious myths are the most frequent reasons individuals and families opt-out or never opt-in to the organ donation process (S. E. Morgan, 2004). Due to lack of knowledge about organ donation and transplantation, myths and misconceptions have dominated the conversation in many minority communities. S. E. Morgan and J. Miller (2002) summed this phenomenon up as a combined lack of awareness that perpetuates barriers that continue to persist as negative ramifications in many minority communities. Additionally, other authors such as (Dunleavy, 2013; Irving et al., 2012; Jacob Arriola, Perryman, & Doldren, 2005; Long et al., 2012; S. E. Morgan, 2006; L. A. Siminoff, Lawrence, & Arnold, 2003), also noted lack of knowledge about the organ donation process, and myths have brought about very negative attitudes in regarding organ donation.

The media through news channels and television shows perpetuate attitudes by displaying the "creepy factor", as S. E. Morgan (2006) phrased it, and other connotations regarding organ transplantation, which reinforces misconceptions. Morgan also contends that many community-based promotion campaigns are not thoroughly based in theory or formative research specific to minority communities. The impact of media portrayals results in misguided societal beliefs about organ donation result in influencing declining registrations.

Print media, news coverage and entertainment programming, can be harmful toward organ donor attitudes. Research suggests that it emphasizes negativity of organ donation by repeatedly reinforcing myths and fallacies. (S. E. Morgan, Harrison, Chewning, Davis, & Dicorcia, 2007; B. Quick, Harrison, King, & Bosch, 2013). However, media can also promote more discussion among minority populations by focusing on specific cultures. For instance, a study by Alvaro, Jones, Robles, and Siegel (2006) customized a media campaign in Spanish language to Hispanic populations in two Arizona counties. The broad audience that media is able to voice can be an incredible tool for educating and lowering myths about organ donation.

The 2012 National Survey of Organ Donation Attitudes and Behaviors cite news, media, internet and other forms of entertainment as the top ten important sources of Information about organ donation (HHS, 2013). This may be attributed to the ability of the media to be rapidly retrieved from memory. This is especially true for individuals whom have never experienced the organ transplantation journey of many families, or actually received an organ transplant. This is an important point toward young adults, as most have never had any experience with organ donation. Therefore, they only have their memory banks from media sources to rely on. This fact further perpetuates inaccurate family conversations that have no backing and further causes a prevalence of low donation rates in all ethnicities (Conesa et al., 2004).

Misconceptions about the integrity of the body

All ethnicities have expressed some type of concern in regards to body mutilation in numerous studies. However, organ transplantation tends to be in direct conflict with some cultural beliefs, which was acknowledged early on in the research (Callender & Washington, 1997; McNamara et al., 1999; S. E. Morgan, 2006). Study respondents have expressed concerns about body integrity which involves preventing the body from being cut after death, and the consequences concerning religious myths, taboos, and bad luck in some minority populations. According to many myths and taboos, death should never be discussed, as it would cause bad things or even premature death to happen. These perceptions extend across minority cultures when dealing with contact with blood of the deceased, which also extends to organ donation. Many religious beliefs do not accept man determining life and death by donation because they feel God will provide if he meant for survival of organ failure patients to happen (S. E. Morgan, 2006) (Wittig, 2001) (Fahrenwald et al., 2010).

Body integrity is a major point of concern in family consent across ethnicities, specifically in Hispanic communities (C. V. Brown et al., 2010). Many have made mention of families wanting the body to stay whole because the deceased would need the organs to reunite the spirit with the body after death (S. E. Morgan, 2004, 2006; Verble et al., 2002). In addition, some African American respondents were concerned about disfigurement and disgust of having the organ of a corpse inside the body. Morgan understood these reactions in African Americans as being cultural and stemming from deep-seated taboos about blood and contact with the dead.

Researchers often overlook barriers such as integrity of the body because it is very difficult to quantify. However, when these important factors are not addressed, promotion campaigns will be less effective because they do not target real problems that hold the key to decision-making and willingness toward organ donation (S. E. Morgan, 2006).

Preservation of cultural traditions and battling the prevalence of diabetes were of concern for the Lakota Sioux American Indian. Many participants felt these organs were needed to help the living. They transitioned to organ donation with the understanding that there was respect for their ancestry, and the deceased body be treated with care and respect. Many modern societies have realized that weighing the importance of tradition and the need to help the sick will require some transition, but the transition must keep in mind the traditions of the past when possible (Fahrenwald & Stabnow, 2005).

Concerns about disfigurement and displaying of the body at funeral services, and mutilation was also cited by (McDonald et al., 2007; S.E. Morgan & Cannon, 2003; B. L. Quick, Lavoie, Scott, Bosch, & Morgan, 2012; Ralph et al., 2014; Verble et al., 2002). Disfigurement and mutilation were one of the highest concerns of families regarding organ donation. Many attitudes in African American populations toward death are rooted in struggle, anger and violence since the earliest days of slavery. Further, African American funerals are highly important to individuals and family members. Open caskets are quite common and disfigurement is a top concern. In addition, African Americans prefer for funerals to take place inside the church (Peveto, 2004).

Medical Mistrust

Medical mistrust in organ donation can be viewed in many ways. The complexities can be viewed separately or comparatively. L. A. Siminoff and Saunders Sturm (2000) explained the state of distrust in minority communities has hampered building stronger ties amid individuals need to involve family members in to designate for decisions against discrimination. Hence, African Americans have placed pronounced significance regarding family donor designation decisions.

Research professionals have emphasized minority attitudes toward historic events such as the Tuskegee Experiment as a betrayal of the healthcare system on African Americans and other minority populations (Callender & Miles, 2001) (Mally & Worrell, 2014) (Minniefield, Yang, & Muti, 2001) (L. A. Siminoff & Saunders Sturm, 2000). The Tuskegee Syphilis Experiment was a study conducted over a 40-year period from 1932 to 1972, by the US Public Health Service. Approximately 600 African American farmers in Alabama were involved in this study for which they were told they were being treated for bad blood. The study was actually initiated to test for untreated syphilis in African American men. None of the participants were ever informed that the study was actually a syphilis study, which was indicative of building mistrust. Of these 600 participants, 399 of these men actually had syphilis. These men were never actually treated for the condition of syphilis, for which a treatment was developed 1947 (CDC.Gov, 2013) (Bowen, 2010). This event has been considered inexcusable in the African American community. In addition, the American Indian population have endured a history of policies and medical mistrust that still lingers into present day questions of mistrust. Currently, the American Indian population has the poorest health outcome of all ethnicities. The American

Indian population has endured several episodes of ethical medical mistrust during 1973 to 1976. Over 3,000 women ages 15 to 44 years of age were sterilized by authority of the Indian Health Service. These women had not consented and were coerced into sterilization by being told they may lose access to benefits or possibly custody of their children (Pacheco et al., 2013). These occurrences of continued medical mistrust throughout history still linger through minority populations and continue to create distrust in younger generations.

The perception that minorities will not receive adequate care or they will experience early death in order to make them organ donors is a myth in minority communities that still exists for many individuals and cultures (Long et al., 2012; Minniefield et al., 2001; S. E. Morgan et al., 2002). The perception of medical mistrust is the most consistent barrier and is perhaps the most cited barrier involving organ donation (S. E. Morgan, 2006; L. A. Siminoff & Saunders Sturm, 2000). Additionally, there is no experimental data substantiating mistrust.

Mistrust in medicine is of specific concern for the American Indian populations because the structure of healthcare populations where they live. Many American Indians have to navigate between several locations for healthcare. As they look to healthcare from various locations, diagnosis and opinions of healthcare professionals change, which leaves the population distrustful about their care and the healthcare system. Additionally, American Indians have little confidence in the healthcare provided and have serious doubts about the healthcare system upholding their traditional cultural beliefs (Fahrenwald & Stabnow, 2005).

Similar studies described attitudes where bias is strongly related to an individual’s willingness toward donation (McNamara et al., 1999; S.E. Morgan, 2004; L. A. Siminoff & Arnold, 1999; Yuen et al., 1998). These attitudes have manifested in a general distrust of the medical system and a belief that a medical practitioner would not save a life if an individual designated himself as a potential organ donor. In addition to knowledge and attitudes, social norms are of primary importance in donation decisions because of the mistrust many share (S. E. Morgan, 2006).

B. L. Quick et al. (2012) questioned individuals about the barriers that create the mistrust among minorities and cause hesitation against organ donation. This study demonstrated how a public health campaign became an instrument to medical mistrust when African American student respondents assumed that only famous people such as professional basketball players received a transplant. The actual ad was intended for inspiration because this particular professional basketball player's struggles were shared via public health messaging. This unintentional barrier shows how research and careful planning are necessary when planning interventions in minority communities. Good intentions can easily work as barriers in subjects that the intended populations are not particularly familiar with, such as organ donation and how the process of procurement and distribution works.

Religion

Most religions support organ donation and transplantation, particularly larger groups such as: Buddhism, Christianity, Hinduism, Islam, Judaism, and Sikhism. These religions focus on the spirit leaving the body and the opportunity to relieve suffering and saving lives is a central component for worshippers (Cook, 2007).

Research has shown by numerous authors the historical relationship that many minorities, specifically Hispanics and African Americans have had with religion and the church. Religion has been an integral part of the minority struggle and the process of organ donation and transplantation in the US (Arriola, Perryman, Doldren, Warren, & Robinson, 2007; Ebadat et al., 2014; Martinez et al., 2001; S. E. Morgan, 2006; S. E. Morgan et al., 2002; Robinson, Klammer, Perryman, Thompson, & Arriola, 2014; Verble & Worth, 2012). The church has supported organ donation by assisting in explaining the fact that there is no biblical text against organ donation and transplantation. However, S. E. Morgan (2006) also noted that there is a lack of active support in minority churches in promoting organ donation. Unfortunately, many negative social and attitudinal barriers have been associated with religion and the afterlife; many of which are based in misperception as a result of lack of education. Despite the fact that most religious cultures have no direct objection toward organ donation, it remains an important barrier for many families (Robinson et al., 2014).

Barriers to Family Donation

Verble et al. (2002) described barriers contributing to Caucasian, African American, and Hispanic family declining of registration. Data were collected from 53 procurement coordinators from 4 OPOs in Arizona and South Carolina from July 1999 to November 2000. The donation rate for this study was 63% consent vs. 36.2% nonconsent of 206 families. The most significant barriers of concern for families who declined consent for organ donation were: (1) Donors expressed wish not to donate; (2) Body needs to be buried whole; (3) Fear of mutilation or disfigurement; (4) Other concerns. Verble et al. (2002) was designed for the purpose of measuring family hesitations and concerns with their donation decision. All ethnicities differed in degrees of concern, but all responses were similar. The study concluded that these four barriers presented the biggest risk for organ donation. It also showed interventions needed customization to the population the intervention is targeting.

Additionally, based on research done in Europe and in the United States, the concern for family statements such as “Donor expressed wish not to donate” was actually a failure of misguided public education and the families' way of articulating other reasons for not donating. If transplant coordinators failed in addressing concerns of family, this expression was a way of terminating the conversation. Additionally, not only did the expression create a barrier in African American respondents; it was a termination of any discussion about organ donation with all African American families, hence these families complied 100% for the deceased wishes of declining donation (Verble et al., 2002).

Lack of Communication Between Family Members

The lack of communication among minority family members concerning organ designation is a key barrier contributing to minority populations having much lower opportunities at receiving transplants than white populations. According to Burroughs, Hong, Kappel, and Freedman (1998), less than half of all families have ever discussed their opinion on organ donation. Family discussion is a key determinant to organ donation (McNamara et al., 1999; Minniefield et al., 2001; S.E. Morgan, 2004; S. E. Morgan et al., 2002; Murray, Miller, Dayoub, Wakefield, & Homewood, 2013; Purnell et al., 2011; Smith, Massi Lindsey, Kopfman, Yoo, & Morrison, 2008). It is the strongest predictor of organ donation especially in minority communities. Exposing information in regards to organ donation is a strong predictor of attitudes and willingness for discussion of organ donation. These discussions are difficult for many families due in part to cultural norms of death being such a forbidden subject of conversation among family members.

Awareness of Organ Donation

Many minority respondents have expressed little to no exposure to knowledge about organ donation except at locations such as department of motor vehicle locations and through the media (Long et al., 2012) (Alvaro et al., 2006). This is troubling as media outlets, specifically entertainment outlets, may provide inaccurate information about organ donation and transplantation. Mass media can distort the process of organ donation and transplantation, therefore It should not be considered a primary source of accurate and consistent information outlet (B. Quick, et. al, 2014).

Knowledge about organ donation has shown direct influence in attitudes about donating. The accuracy in knowledge passed between family members is exponentially important for family donation. Public education also encourages family discussion, and enriches understanding of organ donation (Waldrop, Tamburlin, Thompson, & Simon, 2004). Minorities are less likely to be aware of the need for organs, as well as a lack of understanding of organ donation and the organ transportation process, simply because there is less access. Hence, general knowledge of the organ donation process is a good predictor of willingness and participation in organ donation (Morgan S.E., 2006).

"Donors expressed wish not to donate"

Potential donor families are often faced with the fact that in addition to the death of their loved ones, they are also being asked to donate organs of their loved ones. Many would rather not deal with any additional stress. Often the answer from families of designated donors is; "Donor expressed wish not to donate", despite the fact that they are registered. After writing the original article; Verble and Worth (2012) 10 years later, attempt a more detailed explanation of the statement, “Donors expressed wish not to donate” from dissenting families. First, they explain that this statement has many meanings. (1) The number one reasoning is that maybe the donor changed their mind about donating and actually did make the statement. (2) Individuals have as many or the same barriers to donation as the family unit. If the potential donor said this was what they wanted for their body, their requests must be respected. (3) Verble goes on to explain, “He said he didn’t want to be a donor” could also possibly mean the deceased made the statement based on bad information. (4) Another reason could be that the families thought the deceased organs were not viable based on behaviors or sickness before death, so they use this phrase to protect their deceased loved ones. (5) Finally, families may have used the phrase because the deceased never stated their intentions about being donors and the family prefers termination the conversation.

Factors influencing Family Decisions to Designate for Organ Donation

Assessing determinants and motivations for designation of organs from various studies and sources assist in contrasting barriers that persist in minority communities. Although all determinants are not controllable, awareness of these facts are very helpful in understanding attitudes and behaviors. L. A. Siminoff, Gordon, et al. (2001) offered factors associated with the decision to donate in a study of 420 eligible patients for which 238 donated. This study revealed many factors associated with willingness toward donation. Families who had prior conversations prior to death were more likely to donate, as were families who had contact with OPO staff.

Primary Factors Important to Designation of Organ Donation

Primary factors associated with willingness to donate are family sociodemographics, understanding brain death, family communication, who raised the issue of donation with the family, OPO related variables such as time spent and communications with family, and timing of request. Similar indicators associated with willingness to designate for organ donation with factors such as; discussion with family or loved ones, belief/trust in doctor, and concerns about disfigurement (McNamara et al., 1999).

Family sociodemographics are very pertinent to registering for organ donation. Individuals with higher education, less traditional religion and prior knowledge about organ donation and transplantation are more likely to donate. There are a few conflicting views about the sex of donors that have shown studies, where women are more likely to have registered for organ donation than men. Additionally, there are also very popular studies that may equally disagree that men are more likely to donate (Irving et al., 2012) (S. E. Morgan & J. Miller, 2002) (L. A. Siminoff, Gordon, et al., 2001) (Thompson, Robinson, & Kenny, 2003). Nonetheless, there are no arguments that young people are more likely to have registered for organ donation than older individuals (HHS, 2013), (L. A. Siminoff, Gordon, et al., 2001).

Families understanding brain death

Most studies similarly agree that families' understanding of brain death as soon as it happens is vitally important. Understanding brain death is not just vitally important to minority communities, it is also important for the general population as well. As many as 18.1% families say they were confused about the time death occurred for their loved ones. Families who do designate manage to continue the donation process despite being somewhat unclear about brain death. Many who are confused can only relate to the time the heart stops, as the time of death (S. E. Morgan & J. K. Miller, 2002; L. A. Siminoff, Gordon, et al., 2001).

The research community tends to agree that not understanding brain death can also be a barrier for many families who disagree that recovery is not possible from brain death and the knowledge given about brain death is not always accepted as truth. When many families are told, their loved ones are brain dead, they never really accept that they are dead. What they actually believe is that their loved ones will never be the same again, but never really consider them dead until their heart stops. These types of misunderstandings lead to barriers of mistrust and lower organ donation rates (L. Siminoff, Mercer, & Arnold, 2003).

Siegel (2009) referenced the Family Communication Coordinator (FCC) Protocol, which is an approach to communicating with donor families early when it is evident patients may be dying or brain dead. The FCC protocol, located in Appendix B, improves organ donation effectiveness by drawing upon pastoral care and research related to organ donation. This protocol outlines a path to promoting families' understanding of brain death and helping families accept the death of a loved one.

As mentioned previously, since studies indicate only a small proportion of the population understand brain death, protocols help in forming understanding and trust in assisting with this type of devastating news. Several studies have shown less than 30% of the population understand the meaning of brain death (L. Siminoff et al., 2003). Therefore, the process of communication must continue in a short period of time for potential donor families. As well, many people refuse to accept brain death if the patient's heart is still beating. The FCC Protocol assists in communicating the condition of potential donors, was developed for pastoral care to improve effectiveness of communicating and promoting families' understanding of brain death and acceptance (Tartaglia & Linyear, 2000) (Linyear & Tartaglia, 1999), (L. A. Siminoff, Gordon, et al., 2001). Once patients are identified a chaplain, who is also a part of the hospital support team, is identified to provide support services for the family during the process of death. The chaplain and other members of hospital staff work to make sure families understand when patients are deceased. Families are not introduced to OPO staff until after it is established they understand that their loved ones are deceased. The importance of family opinions when increasing conversion rates for organ transplantation is extremely important. Although conversion rates are not usually a goal of an FCC, it should also never be under estimated (Siegel, 2009).

Socioemotional and communication process variables

Although socioemotional variables are not directly related to family decision-making, it is a very important component related to decision-making. For instance, it is important that families believe their loved ones were cared for in the best way before death, for successful outcomes after death. Families who perceive HCPs are non-caring about their loved ones will have a lower opportunity of donation (56.6% vs 43.4%, P=0.04). More direct factors such as families being surprised by being approached and family members feeling pressured were also less likely to donate (66.0% vs 34.0%, P < 0.001) (L. A. Siminoff, Gordon, et al., 2001).

Families who are surprised in being asked the donation question in regards to their loved ones feel harassed and are less likely to designate consent for donation. Therefore, the approach must be well thought out since the initial reaction is strongly associated with the final decision of organ donation. When HCPs came in contact with families initially, the rate of willingness to donate and initial reaction went down to less than half (46.9%); whereas when families were approached by OPOs in regard to initial reaction, their consent rates were (71.6% vs 28.4%, P <.001). Talking with OPO staff before being asked for a donation consistently produced positive results (L. A. Siminoff, Arnold, & Hewlett, 2001) .

Organ Procurement Organization Request Related Variables

Several Studies have shown that talking with grieving families is a skill that must be mastered in order to obtain the willingness sought for organ donation. L. A. Siminoff, Gordon, et al. (2001) detailed how HCPs showed lower results in persuading families to donate loved one’s organs as were several studies suggesting OPOs are in a better position to ask the question. This may be in part to families depending on HCPs to care for their loved ones. The discussion of organ donation could possibly make families feel that the HCP is not doing everything they can to prolong the life of loved ones.

Factors directly associated with OPO success are associated with not taking families by surprise or being overly aggressive before making the request, and additionally, never assuming who will donate. L. A. Siminoff, Gordon, et al. (2001) showed 46.9% of HCPs correctly determined families’ initial response to requests for organ donation is critical. Additionally, families who had better connections with HCPs in initial reactions to requests were more apt to donate a loved one’s organs by a margin of (66.0% vs 34.0%). Therefore, conversations with OPO’s are critical. It is important that quality discussions occur prior to asking for the donation.

Timing of Request

There are opposing views about timing of donation requests and how it affects consent rates. Differences in approaches are more of a testament that these situations must be analyzed on an individual basis before opening up the conversation. Both views show advantages and disadvantages. The research shows instances where requesting donation right after or before patients are pronounced can be received negatively and the donation process is terminated. However, there is a limit to waiting too long in presenting the request; putting the requestor in the position of surprising the next of kin, and surprises are very undesirable. The research also emphasizes that the request must come from the right person for good outcomes (Browne, 2010; L. A. Siminoff, Gordon, et al., 2001; Traino & Siminoff, 2013).

Family Discussion

The consequences of families' communication regarding organ donation intentions are much more important than the act may seem. However, overcoming social norms for individuals and families is difficult, but may be even more difficult for several reasons in order for the conversation to occur. These discussions can also be very sensitive and difficult because individuals do not like thinking about their own demise. Even when these discussions are initiated, many are short or flipped because the topic is so uncomfortable. These situations are often the reason families decline donor organ donation as they are not clear of the loved one's ultimate designation. Family discussion is healthy because they promote understanding and attitude and willingness toward communication and organ donation (S. E. Morgan, 2006; S. E. Morgan & J. K. Miller, 2002).

Donor Authorization (First Person Consent)

End-of-Life policies in the US embody the right to self-determination, giving individuals the right to determine their own existence. The Patient Self Determination Act (PSDA) reinforces these rights for individuals to accept or refuse medical care at will. Further, the Uniform Anatomical Gift Act (UAGA), was created to sustain and extend life through life support. UAGA was amended in 2006 for the purpose of using life support to extend the use of aided devices for the express purpose of organ donation. UAGA was also revised to add Donor Authorization or (First Person Consent) legislation. First Person Consent gives donors the right to uphold their wishes in regards to their organs after death. Verheijde, Rady, and McGregor (2007) interpretation of this revised Act is; 'if a donor has signed up to designate the gift of life, there is no reason to seek consent from the donor's family'. This is a far different protocol from what has been a standard of seeking the next of kin's consent to remove organs from a designated donor.

Families expressing designated deceased opinions such as "Donors expressed wish not to donate" or "He said he didn't want to donate", has been an obstacle for donation since the program began. When even one family declines a designated donor, they affect the lives of up to 8 other families. Based on the fact that a deceased donor has the ability to replace 8 organs in organ failure patients, UNOS decided to act in favor of the donor. UNOS established First Person Consent legislation to enable states the right to claim more designated organs for transplant in order to insure better outcomes for organ failure patients waitlisted for transplant (Christmas, Burris, Bogart, & Sing, 2008). Though these new laws would prevent family members from overriding donor designations, it is still vitally important for families to be aware and at peace with the donors' decision. Communication among families regarding posthumous decisions is still vital and necessary for several reasons. Making decisions before death relieves family members from having to guess what the deceased would have wanted.

Every state in the US now has First Person Consent legislation in place, but not all states are enforcing these new laws. The Joint Commission (2004) issued its opinion that most hospitals and OPOs were not enforcing First Person Consent in fear of litigations from family members and loved ones; but research is showing success in communicating with families and recovery rates of special situations where First Person Consent was used to procure organs. However, if and when Health Care Professionals (HCPs) and Organ Procurement Organizations (OPOs) were ready to begin enforcing First Person Consent, policies are in place to protect them from any legal ramifications according to L. A. Siminoff, Agyemang, and Traino (2013).

L. A. Siminoff et al. (2013) cited the circumstance that not everyone will see First Person Consent as a way of protecting the autonomy of the patient or donor. Siminoff argues that First Person Consent laws are effectively being enforced under the assumption that most designated donors want to donate, but were failed by the health system and this problem would now be alleviated by First Person Consent legislation. However, how or in what manner was the request for designation made to the donor; and perhaps the family does have knowledge of the donor’s wishes contrary to what the registry may state. Early impact shows the effectiveness of First Person Consent is very positive. Many reference UNOS and the research obtained from surveying registered donors as positive reasons for moving forward First Person Consent legislation. Additionally, Appendix C shows the rate of minorities on the waiting list in the United States as of August 2016.

Rodrigue, Cornell, and Howard (2006) also show favorable attitudes toward First Person Consent in a survey administered to 456 next-of-kin donors. However, similar to Verble and Worth; Rodrigue et al. (2006) also advised education on First Person Consent should be required before implementation as several researchers have suggested previously.

The State of Ohio was one of the first states to implement First Person Consent legislation. Ohio changed its donor registry to a First Person Consent Registry in 2002. This registry, which became known as The First Person Consent Ohio Donor Registry (1stPCODR), was rolled out with an educational program bringing awareness to the shift in giving donors the only authority to designation of their own organs. This statewide educational campaign consisted of television advertising, radio and public service announcements. Additionally, a 4-year study was performed showing the effectiveness of the new legislation through the Health Resources and Services Administration, Division of Transplantation (HRSA/DoT), U.S. Department of Health and Human Services (DHHS). This study showed a shift in attitude and willingness for acceptance of passing this responsibility away from the family. Healthcare networks changed their protocol toward accommodating First Person Consent based on the fact there have been no lawsuits since First Person Consent legislation was introduced and implemented (Cook, 2007).

Ethics in Organ Donation

The principles of Utilitarianism or "*The Greatest Good For The Greatest Number*" involve the overall goal of bringing maximum pleasure and welfare or total well-being for the greatest number of people (Beauchamp & Steinbock, 1999).   Likewise, OPTN's goal is procuring organs intended for transplant for the greatest good of humanity, recognizing this action does come with some pain and sacrifice. Organ transplantation is an overall good alternative for maintaining life, therefore when measuring the quality of life, transplantation is more of a collective net good.

OPTN strives for justice and making organ procurement an unbiased process of allocating the Gift of Life equitably for all. Respect requires that all people are unconditionally treated with value, and every individual is able to maintain autonomy as well. All methods of organ distribution should give all candidates an equal opportunity for transplantation with equal respect and care for each patient. All candidates should be entitled to equal access. Additionally, OPTN is mandated to oversee and ensure that it considers all factors with justice when considering the distribution of organs (OPTN, 2016b).

OPTN (2016a) used the Belmont Report as a basis for assuring respect for all people. It summarizes ethical principles around respect for persons. The organ donation and transplantation process also comprises the concept of respect for individual's autonomy. OPTN described these 5 factors in respect to autonomy for all:

1. The duty to respect decisions of donors or those who refuse to donate organs.
2. The right to refuse an organ.
3. Free exchanges among autonomous individuals.
4. Allocation by directed donation.
5. Transparency of processes and allocation rules to enable stakeholders to make informed decisions.

https://optn.transplant.hrsa.gov/resources/ethics/ethical-principles-in-the-allocation-of-human-organs/

Additionally, if ones autonomy conflicts with ethical principles, the common good should be considered and precedence given to the best outcome (OPTN, 2016b).

Organ Donation Education

Education can be very broad in terms of the field of organ donation and transplantation. The Institute of Medicine and various other organizations have cumulatively recommended some form of education to all stakeholders, from physicians, to donor families, recipients families, the general public and minority populations (Institute of Medicine, 2006). These forms or donation education come at different levels and are meant for various audiences. Donation education empowers families and helps them move toward making informed choices as well as strengthens autonomy. Previous research from Radecki and Jaccard (1997) emphasized that educational programs provide a direct path to accurate information, awareness and also helps in dispelling myths. However, based on educational programs established across the US in Appendix C, many states may not have adequate education for basic organ donation education.

A key factor in increasing rates of organ donation in the US is a knowledgeable community. Having the information necessary in making informed choices is essential and is the basis of individual autonomy. Increasing public understanding of donation education through national and local organizations with culturally sensitive educational materials should be dispensed at various levels of education that give recipients accurate portrayals of organ transplantation (Institute of Medicine, 2006).

The research suggests that education and outreach are still very relevant and important in improving donation rates among minority populations (C. V. Brown et al., 2010). Additionally, S. E. Morgan (2006) and the Institute of Medicine (2006) referenced the importance of using education in explaining organ donation and transplantation, which supports the continuing problem of dispelling and debunking myths, misinformation, and misperceptions.

Organ donation education has leaned strongly toward nonprofit organizations delivering public health education through public health campaigns. Education in minority populations must provide accurate information, that is culturally directed toward awareness of the disparities between potential donors and waitlisted organ failure patients (Long et al., 2012). The Minority Organ Tissue Transplant Education Program (MOTTEP) focuses on educational minority media campaigns and grassroots public education programs of this nature. Community grassroots educational programs are important for minority communities to address particular ethnical, cultural and religious concerns that national campaigns do not have the capability to do (Institute of Medicine, 2006). These programs are also great for building coalitions and partnerships with local organizations.

Providing donation education to students is particularly important for young people. Driver education has been the principle form of education for youth, with organ donation as a subset. Additionally, in 2004 HRSA established “Gift of Life Initiative”, an educational program distributed to driver education teachers for high school students nationwide (R. S. Brown et al., 2009). Currently 16 states require driver education classes include organ donor education and 10 states have some form of education for students that are not necessarily mandated (OPTN, 2016b). States are responsible for their own forms of education in regards to organ donation. Appendix A shows the need for educational programs to coincide with First Person Consent, and driver safety in many states. There are even less independent education programs providing education regarding organ donation, according to data provided by UNOS.

Chapter 3 - Methodology

Data Sources

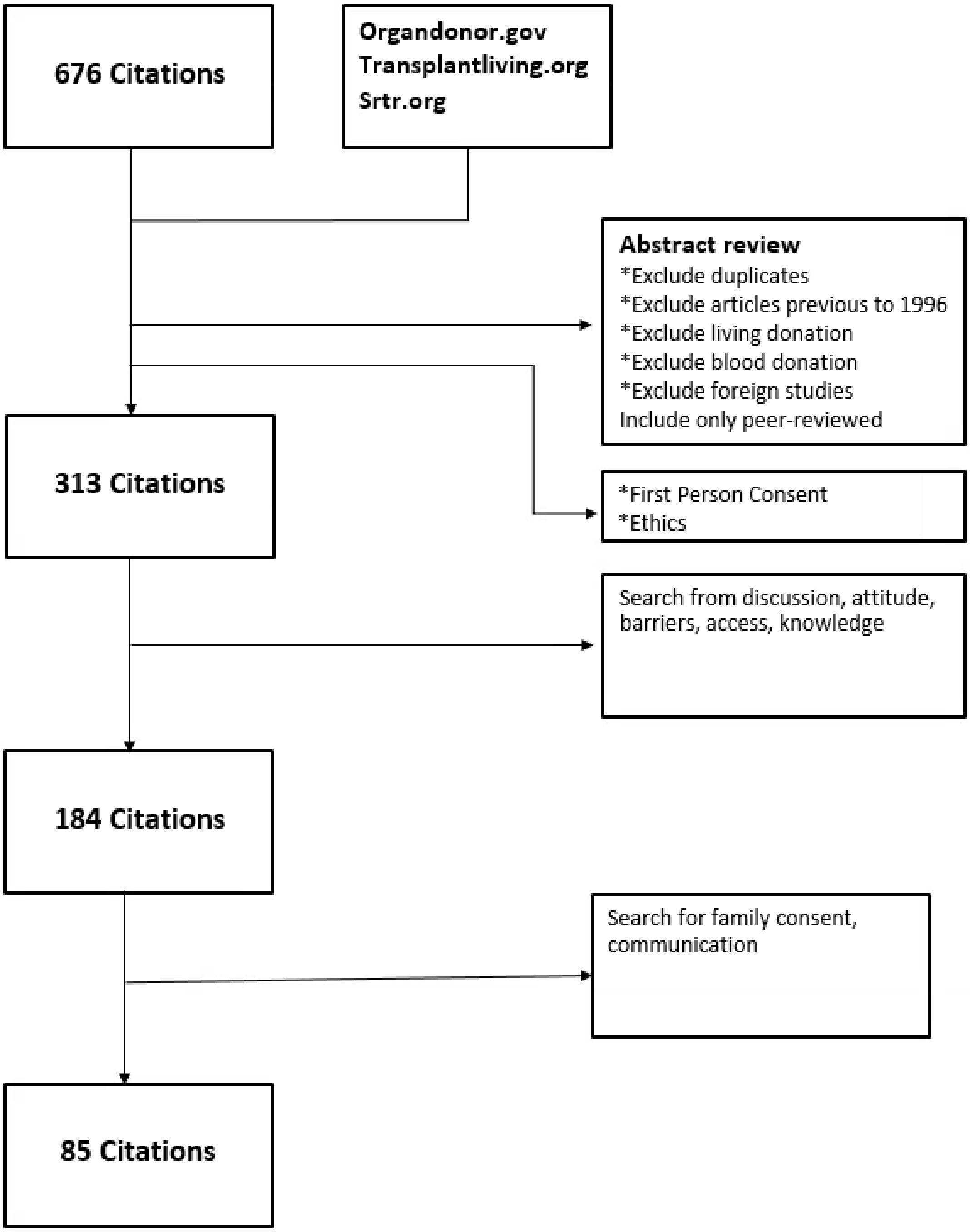
This study was a non-experimental cross-sectional systematic review using secondary data from Medline, EMBASE, EBSCO, and Web of Science, Ovid, Elsevier, ProQuest, Sage, and Google Scholar. Articles were selected based on subjects related to organ donation such as family, culture, ethnicity and attitudes. Studies involving questionnaires included questions regarding types of discussion with next of kin and “Did family know patients’ intentions” were of particular interest.

Variables

This study measured variables such as attitude and willingness to donate, as well as (consent and non-consent) next of kin and loved ones. Other measures included self-identified families who have or have not had end-of-life conversations with loved ones. The following search terms were used separately and in combination: “Organ donation”, “Organ transplant”, “Organ donation family discussion”, “Organ donation family communication”, “Organ donation factors”, “Organ donation barriers”, “Donor Authorization”, “First Person Consent organ donation”, “Organ Donation Ethics”, “Brain death”.

Specific data on living and tissue donor information were excluded as well as blood donation. Specific information on communication between OPO’s and HCPs was excluded unless it was directly related to communication with donors and donor families. Some tables and figures were combined from peer-reviewed secondary information with an effort to extract specific data.

Figure 2. Systematic Review Study Selection



Chapter 4 - Results

Study Selection

A total of 676 studies were initially selected using the following key word phrases: organ donation consent, designation, minority consent, and First Person Consent (Figure 2). After closer analysis, documents were searched for phrases in relation to attitude, family, willingness, and populations, of which, left 313 studies eligible for use. Choices were narrowed down further by searching for variables such as discussion, barriers, access and knowledge, which narrowed studies down to 184. Finally, after reading and searching through abstracts and methods, terms such as the consent and/or communication were chosen to be used for this study. This criterion produced a total 85 documents with 12 core documents regarding the subject of communication were included in this review.

Studies conducted outside the US were excluded, unless the study was done in combination with US populations combined with foreign studies. Studies conducted before 1996 were also excluded as a result of this particular study extending back 20 years (1996 – 2016). This study was a mixed methods design, based on secondary analysis of peer reviewed studies, and specific factors related to minority attitudes and behaviors toward organ donation.

The aim of this study was to explore willingness and attitudes toward communication and discussion between family members regarding organ donation among minority populations. Several studies showed the connection of various predictors such as sociodemographics, education, awareness, cultural norms, support systems, education level, knowledge, mistrust, and beliefs in connection with family communication and discussion.

Themes and Findings

This systematic review is based upon core studies that focused on minority populations, attitudes, willingness, behavior, communication and discussion among minority family members regarding registering or declining organ donation. These studies were very similar in many facets such as the state of minority attitudes and reluctance toward donation. More importantly, these studies analyzed the difficulty of pinpointing the cause(s) many minorities opt against designating for organ donation. Four studies explored the relationship in attitudes, beliefs, and prior knowledge in relation to organ donation. These studies are usually related to barriers that assist in shaping individual and family hesitations about negative attitudes in organ donation. Three studies emphasized the differences and relationship between consent and non-consent families. Prior knowledge and the decision to donate were explored in four studies which included numerous references to distrust due largely to lack of access or exposure to organ donation and transplantation information. Finally, two studies explored the relationship between consenting to donation and previous discussion families may have had prior to designating or declining donation. They show the relationship between open discussion, death planning and family behavior when this connection is in place.

Ten of the 12 core articles selected for review had a total number of respondents totaling less than 500 people. This core group, listed in Table 2 are articles that explore characteristics and behaviors that affect organ donation decisions. Several articles selected for review tended to lean heavily toward African American populations and the significant prevalence of organ failure due to diabetes and high blood pressure. These studies also emphasized the critical state of organ demand, supply and attitudes in African American populations (Table 2).

Table 2. Attitudes and Behaviors Toward Organ Donation

Author (s) / Year	Study Period	Cases	Ethnicity	Title/Design	Family Discussion and Communication	Objective/ Population
Brown, C, Foulkrod, K.H. (2010)	JAN 2004 – DEC 2007	827	314 – Cau 55 – AA 441 – Hisp	Barrier to Obtaining Family Consent for Potential Organ Donors/Retrospective Analysis	Potential organ donor families who declined organ donation (decline group) were compared with potential organ donor families who consented to donation (consent group).	Barriers persist to family consent for successful organ donation. / Family/Next of Kin
Dodd-McCue, D., & Tartaglia, A. (2007)	1997 – 2004	120	African American	African American consent and nonconsent cases: are there significant differences? / Exploratory retrospective Nonexperimental	Donor wishes shared with family through communication and family discussion was more significance in donor families than in nondonor families	Examines differences between African Americans who consent and those who don't consent. /Academic Medical Center
Fahrenwald, N.L., Stabnow, W. (2005)	Unknown	21	Oglala Lakota Sioux Indian	Sociocultural Perspecitive on Organ and Tissue Donation among Reservation-Dwelling American Indian Adults. / Qualitative ethonographic interviews	Promoting family conversation among potential donor families with respect to traditional beliefs and respect for the process of family communication about organ and tissue donation.	Determine the sociocultural patterns that influence decision about organ donation among Indian adults.
Long, S. D., Morgan, S. E., et al (2012).	Unknown	20	African American Family Dyads	When Families Talk: Applying Interpretative Phenomenological Analysis to African American Families Discussing Their Awareness, Commitment, and Knowledge of Organ Donation / Qualitative interpretative phenomenological analysis	African American family discussion about organ donation could carry negative consequences if family members are deeply rooted in beliefs about organ donation. Studying how families communicate is critical.	Explores African American level of awareness commitment, and knowledge of organ donation. / Urban Metropolitan Southern City
McNamara, P., Guadagnoli, et al (1999)	Dec 1992 – Jan 1993	6080	4880 – Cau 634 – AA 566 – Hisp	Correlates of support for organ donation among three ethnic groups. / Random Survey	Family discussion was associated to willingness to donate across ethnicities. Public education campaigns help to emphasize the need for family discussion.	Study sample beliefs, attitudes and knowledge concerning organ donation. / Telephone Interviews of OPOs
Morgan, S., Miller, J.K., (2001)	Unknown	798	708 – Cau 63 – AA 7 – Asian 7 – Other	Beyond the Organ Donor Card: The Effect of knowledge, Attitudes, and Values on Willingness to Communicate About Organ Donation to Family Members / Questionnaire	Willingness to communicate about organ donation. Knowledge and attitude promote family discussion.	Determine the point to which willingness to communicate about organ donation is an achievable and the association of attitudes, knowledge, and altruism on willingness to discuss organ donation.

Morgan, S. (2004)	Unknown	311	African American	The Power of Talk: African Americans / Survey	The strongest predictor of consent to donate is family discussion. There is a strong relationship between willingness to donate organs and family discussion.	Attitudes, behaviors and willingness of African American families to engage in family discussion. / Random/New Jersey
Morgan, S. E. (2006)	Unknown	310	African American	Many facets of reluctance: African Americans and the decision (not) to donate organs / Questionnaires	Attitude and beliefs are profound and deeply rooted in African American communities. Family discussion is critical in African American families and increase in donation rates are likely to follow.	Relationship of knowledge and attitudes among African Americans. / NAACP members in New Jersey
Purnell, T.S., Powe, N.R., (2011)	May 2004 – Aug 2005	307	167 – Cau 53 – AA 70 – Hisp	Donor Designation: Racial and Ethnic Differences in United States Non-Designators' Preferred Methods for Disclosing intent to Donate Organs / Cross sectional questionnaire	Designator and non-designator preference for discussion with family members and other representatives.	Public Attitudes about organ donation and method of disclosing intentions. / Adult Nondesignators
Siegel, J. T. (2009)	N/A	N/A	Multiple	Understanding Organ Donation Applied Behavioral Science Perspectives.	Family discussion helps families with distrust issues, overcome fears about organ donation. Qualitative studies help to explore behavior and hesitation about discussion organ donation.	Overview of the current situation, highlighting the challenges, summarizing past research, and providing guidance for future research.
Siminoff, L. A., Gordon, N., et al (2001)	1994 – 1999	420	Multiple (Consent and Nonconsent cases)	Factors influencing families' consent for donation of solid organs for transplantation / Chart review and telephone interview	Health Care Practitioners and OPOs discussion with family should be one of correction on misinformation and fears about organ donation.	Explores factors associated with decision to donate among families of potential organ donors. / OPOs, HCPs in Pennsylvania and Ohio.
Verble, M., Gordon, G.R.	Jul – 1999 Nov - 2000	323 Families	211 – Cau 66 – AA 35 – Hisp 11 - Other	A multiethnic study of the relationship between fears and concerns and refusal rates	Family donation discussion with OPOs and their decisions to donate or decline for organ donation. Family discussed fears and concerns related to organ donation.	Procurement coordinators collection of families' expressions regarding barriers to their decision to donate. / Procurement coordinators

Cau = Caucasian AA = African American Hisp = Hispanic

Synthesized studies addressed six themes related to minority donation including sociodemographics, support for organ donation, social influence, attitude and willingness toward donation, prior exposure to organ donation, communication and discussion among next of kin. Specific attention was focused on minorities and barriers involved in decision-making toward organ donation. Characteristics in reference to family discussion, and how donation discussions influence organ donation were also explored. The methodology of The Organ Donation Model assisted in focusing on the balance of how attitude, willingness, culture and knowledge assist in expressing one's beliefs about organ donation.

Sociodemographics of Organ Donation

Sociodemographics were very similar when comparing all studies. Three studies were synthesized to form very common profiles of donor demographic similarities. However, there were some differences in studies when analyzing genders and donation behaviors. Most studies leaned toward females as more frequent in organ donor registrations. Additionally, the 2012 National Survey of Organ Donation list of sociodemographics indicated very close similarities toward core studies chosen for this study. Those sociodemographic characteristics of individuals who lean towards designate more were females, with some college education, young adults, and Caucasians. Those who lean towards declination were more likely males, high school or less education, older adults, African Americans, Asians, Native Americans, and Hispanics. These demographics of organ donation referenced from 2012 National Survey of Organ Donation Attitudes and Behaviors are summarized in Table 3, (HHS, 2013).

Table 3. Demographics of Organ Donation

	Designated	Have Not Designated
Male	45.5	52.5*
Female	54.5*	47.5
High school or less	35.5	54.3*
Some College/Vocational	31.2*	24.9
College or higher	33.3*	20.8
Aged 18-34	33.6*	25.8
Aged 35-54	35.5	34.9
Aged 55-65	17.3	20.1
Aged 66 and older	13.7	19.3*
White	82.8*	70.2
African-American	7.4	16.9*
Asian	3.6	4.0
Native American	1.2	2.1
Multi-Race	2.3	2.2
Hispanic	11.4	19.3*
Non-Hispanic	88.6*	80.7

*Denotes statistically significant difference at the 95 percent confidence level

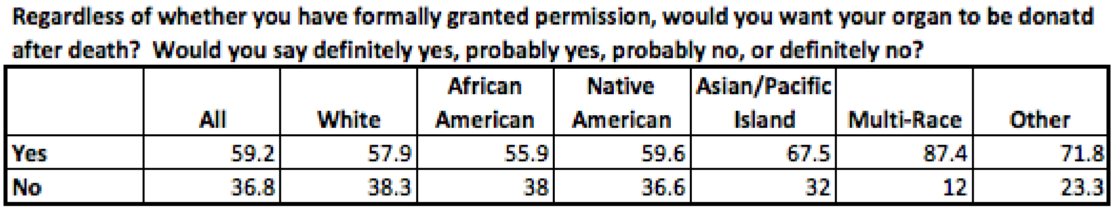
2012 National Survey of Organ Donation Attitudes and Behaviors

Support for Organ Donation

While transplants have been performed since the 1960s, many individuals still reject the act of organ donation and transplantation. Although there is positive support for organ donation in many studies, research shows the actual people who designate for donation show much less support. The 2012 National Survey of Organ Donation Attitudes and Behaviors showed 36.8% of respondents were opposed to organ donation and only 59.2% were at least open to the thought of donation after death (L. A. Siminoff et al., 2003) (HHS, 2013). Support by ethnicity, regardless of whether they have formally designated for donation was proportioned at 57.9% for Caucasians, 55.9% for African Americans, 59.6% for Native Americans, 67.5% for

Asian/Pacific Islands, and 87.4% Multi-Race. These 2012 National Survey of Organ Donation Attitudes and Behaviors are summarized in Table 4.

Table 4. Desire to Have One's Organs Donated After Death, 2012



Regardless of whether you have formally granted permission, would you want your organ to be donatd after death? Would you say definitely yes, probably yes, probably no, or definitely no?

	All	White	African American	Native American	Asian/Pacific Island	Multi-Race	Other
Yes	59.2	57.9	55.9	59.6	67.5	87.4	71.8
No	36.8	38.3	38	36.6	32	12	23.3

(OrganDonor.gov, 2012)

Regarding demographics within families, studies such as C. V. Brown et al. (2010) found similar results as those in the 2012 National Survey. Families who decline organ donation tend to be donors 50 years or older (43% vs. 34%, $p<0.001$); more medical deaths (72% vs. 58%, $p < 0.001$); members of minority families leading in declinations (67% vs. 43%, $p < 0.001$); and finally the time from declaration of brain death to the time that family was approached by OPO for minority families were twice as much as Caucasian families (350 minutes vs. 112 minutes, $p < 0.001$).

Barriers such as perceived religious objections, distrust, premature death, and definition of death, remain dominate objections for donation. Major family barriers recorded by families were declinations based on donor’s wishes ranked as high as 21%, body mutilation at 19%, family wanted closure was 15%, other/or reason not given was 13%, family divided on decision was 12%, patient wishes unknown was 9%, family did not accept brain death was 5%, time constraints was 5% and religious beliefs were 2% (C. V. Brown et al., 2010).

Boulware et al. (2002) conducted a study showing barriers to solid organ donation was adjusted for spirituality and religion. These differences in willingness were increased by 4% - 9% for race and gender, while increasing willingness to donate was increased to align more with the largest group of donors, which were the Caucasian males. Furthermore, adjusting for mistrust increased willingness by 4% - 7%, except for African American males who remained significantly less willing to designate for organ donation.

Concerns of body integrity create significance in predicting whether individuals will designate for organ donation, specifically among minorities (S. E. Morgan, 2006). Family concerns of disfigurement were very significant among those families who chose for or against organ donation. Verble et al. (2002), showed of the 78.6% of African American families and 57.1% in Hispanic families concerned about disfigurement did not donate, whereas Caucasians refusal rate was a low 23% (Table 5). Transplant coordinators also reported numerous family concerns with the donor's body looking disfigured. Verble et al. (2002) showed 134 out of 206 or 65% of respondents were concerned about the body "looking strange" at funeral services, as well as having the possibility of delaying funeral services to perform organ donation and/or mutilation of the body. Table 5 shows a list of concerns documented by Verble et al. (2002), where ethnicities who refused donation and the degree of concern about body disfigurement.

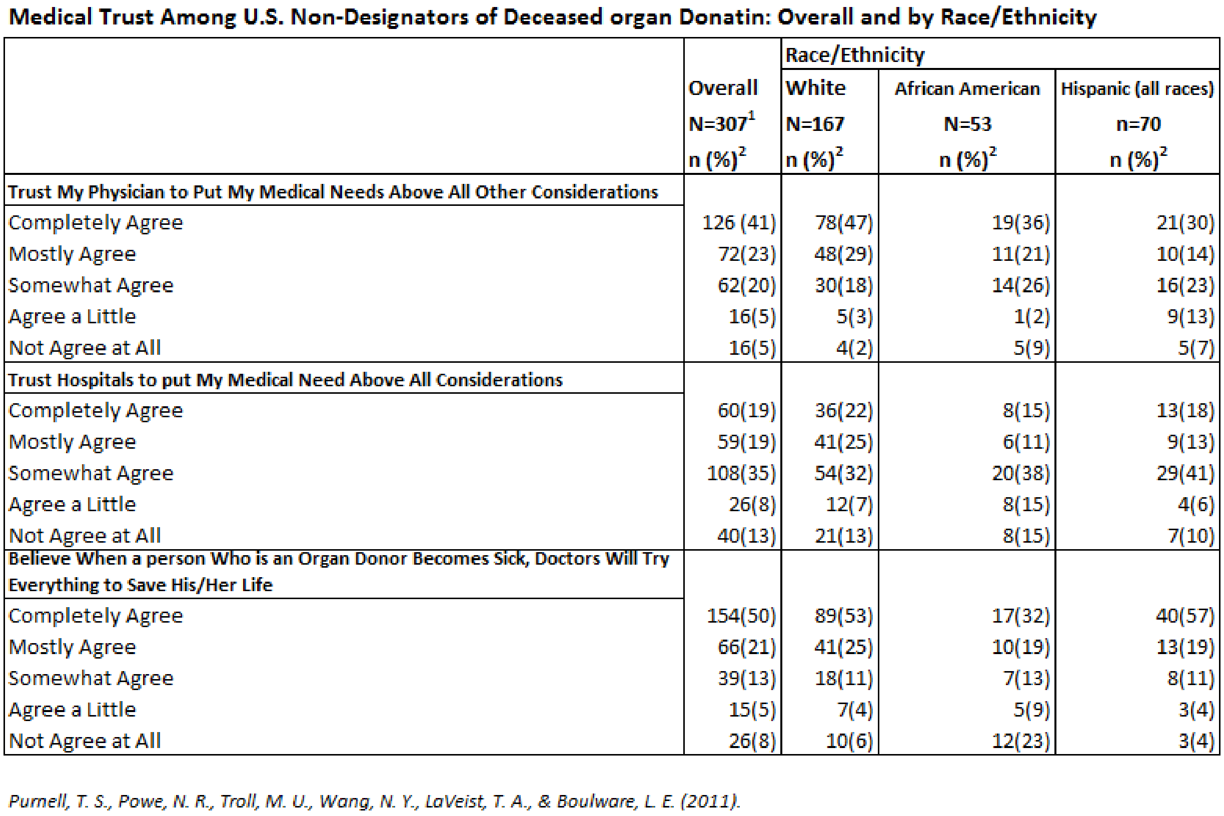
Distrust of the healthcare establishment was a key factor related to willingness and designation for organ donation. Despite the fact that distrust is generally speculative and there is no solid evidence to support these perceptions in organ donation, distrust remains a high concern (S. E. Morgan, 2006). Several studies referencing medical staff hastening a donor's death was of utmost concern (Irving et al., 2012) (Korda, Wagstaff, & McCleary, 2007). Distrust in physicians and hospitals has been associated with nondisclosure or the perception that hospital staff withhold information from family members about donation wishes of donors. Non-designators of all ethnic groups with distrust in healthcare stated they would prefer to disclose their donation designation to a physician at a rate of 65% or family member at 63%. African American men were considerably more likely to believe doctors will not save them if they know another patient needed an organ (Boulware et al., 2002; Purnell et al., 2011) . Data compiled from Purnell et al. (2011) show a low level of trust in both African American and Hispanic populations in Table 6. African Americans and Hispanics were significantly less likely than Caucasians to fully trust their physicians to put their medical needs first. African Americans and Hispanics scored more negative attitudes when comparing Caucasians on all 3 questions of distrust of doctors, hospitals, and whether life saving measures would be executed to save that individual’s life.

Table 5. Concern Given to OPO for Families Who Refused Donation

Hispanic Families	**% of families who had concern**	**% of families with concern who refused donation**	**African American Families**	**% of families who had concern**	**% of families with concern who refused donation**	**White Families**	**% of families who had concern**	**% of families with concern who refused donation**
n=17			**n=46**			**n=164**		
Body needs to be buried whole	29.4	83.3	Other concerns	34.4	93.3	Donor expressed wish not to donate	47.9	88.5
Donor expressed wish not to donate	23.5	66.7	Donor expressed wish not to donate	23.9	100	Hard to decide for someone else	22.9	55
The operation is mutilating or disfiguring	**23.5**	**57.1**	**The operation is mutilating or disfiguring**	**23.9**	**78.6**	**The operation is mutilating or disfiguring**	**18.8**	**23**
Hard to decide for someone else	23.5	80	Body needs to be buried whole	21.7	83.3			
Donor might not be dead	17.6	37.5	Hard to decide for someone	15.2	70			
Body part might be needed in the next world	17.6	75						

Verble, M., Bowen, G. R., Kay, N., Mitoff, ., Shafer, T. ., & Worth, . (2002). A multiethnic study of the relationship between fears and concerns and refusal rates. Prog Transplant, 12(3), 185-190.

Table 6. Trust Among U.S. Non-Designators of Deceased Organ Donation: Overall and by Race/Ethnicity



Medical Trust Among U.S. Non-Designators of Deceased organ Donatin: Overall and by Race/Ethnicity

		Race/Ethnicity		
	Overall N=307[1] n (%)[2]	White N=167 n (%)[2]	African American N=53 n (%)[2]	Hispanic (all races) n=70 n (%)[2]
Trust My Physician to Put My Medical Needs Above All Other Considerations				
Completely Agree	126 (41)	78(47)	19(36)	21(30)
Mostly Agree	72(23)	48(29)	11(21)	10(14)
Somewhat Agree	62(20)	30(18)	14(26)	16(23)
Agree a Little	16(5)	5(3)	1(2)	9(13)
Not Agree at All	16(5)	4(2)	5(9)	5(7)
Trust Hospitals to put My Medical Need Above All Considerations				
Completely Agree	60(19)	36(22)	8(15)	13(18)
Mostly Agree	59(19)	41(25)	6(11)	9(13)
Somewhat Agree	108(35)	54(32)	20(38)	29(41)
Agree a Little	26(8)	12(7)	8(15)	4(6)
Not Agree at All	40(13)	21(13)	8(15)	7(10)
Believe When a person Who is an Organ Donor Becomes Sick, Doctors Will Try Everything to Save His/Her Life				
Completely Agree	154(50)	89(53)	17(32)	40(57)
Mostly Agree	66(21)	41(25)	10(19)	13(19)
Somewhat Agree	39(13)	18(11)	7(13)	8(11)
Agree a Little	15(5)	7(4)	5(9)	3(4)
Not Agree at All	26(8)	10(6)	12(23)	3(4)

Purnell, T. S., Powe, N. R., Troll, M. U., Wang, N. Y., LaVeist, T. A., & Boulware, L. E. (2011).

Social Influence

Two studies focused on social influence in minority populations and their willingness in registering for organ donation. Social norms or social influence have been the focus of various studies since the late 1990s. Social norms are important factors in designating for organ donation because the power other family members have on persuading individuals to register or decline is significant (S. E. Morgan, 2006). Measuring sociocultural influence in organ donation decision making is vital, as many individuals do tend abide by their cultural traditions of which may conflict with organ donation. However, at times these values occasionally create conflict with the decision toward designating for organ donation. S. E. Morgan (2004) cited as much as 25% of Hispanic families' objection as extremely important toward their decision to donate, and African Americans were even more pronounced than Hispanics.

S.E. Morgan (2004) performed bivariate correlations between social norms and willingness in discussing organ donation, r(308) = 19%, p = .001, additionally religious social norms correlated to, r(308) = 18%, p = .004. These frequencies were favorable social norms that connected willingness in talking about organ donation within family members.

Attitude and Willingness to Donate

(McNamara et al., 1999; Minniefield et al., 2001; L. Siminoff et al., 2003) are all similar studies that analyzed willingness in discussing organ designation as well as willingness to donate. Table 7 condenses all three studies to show the contrast among minority willingness as a result of previously discussed barriers. These studies measured willingness in various forms by telephone interview, survey, chart review, transplant coordinators and interviews with the families of deceased. L. Siminoff et al. (2003) revealed Caucasians were more likely than African American patients and families in believing that their family members did want to donate (59.4% vs. 39.3%; p=0 .004). Caucasian families were more likely in having knowledge of their loved ones wishes than African Americans (72.9% vs. 49.0%; p=0.0001). One point of some significance was that HCPs and OPOs were predominately Caucasian. Additionally, HCPs misclassified 23.5% of African American families as favorable or unfavorable. As well, African Americans self-reported, they had less discussions about organ donation issues than

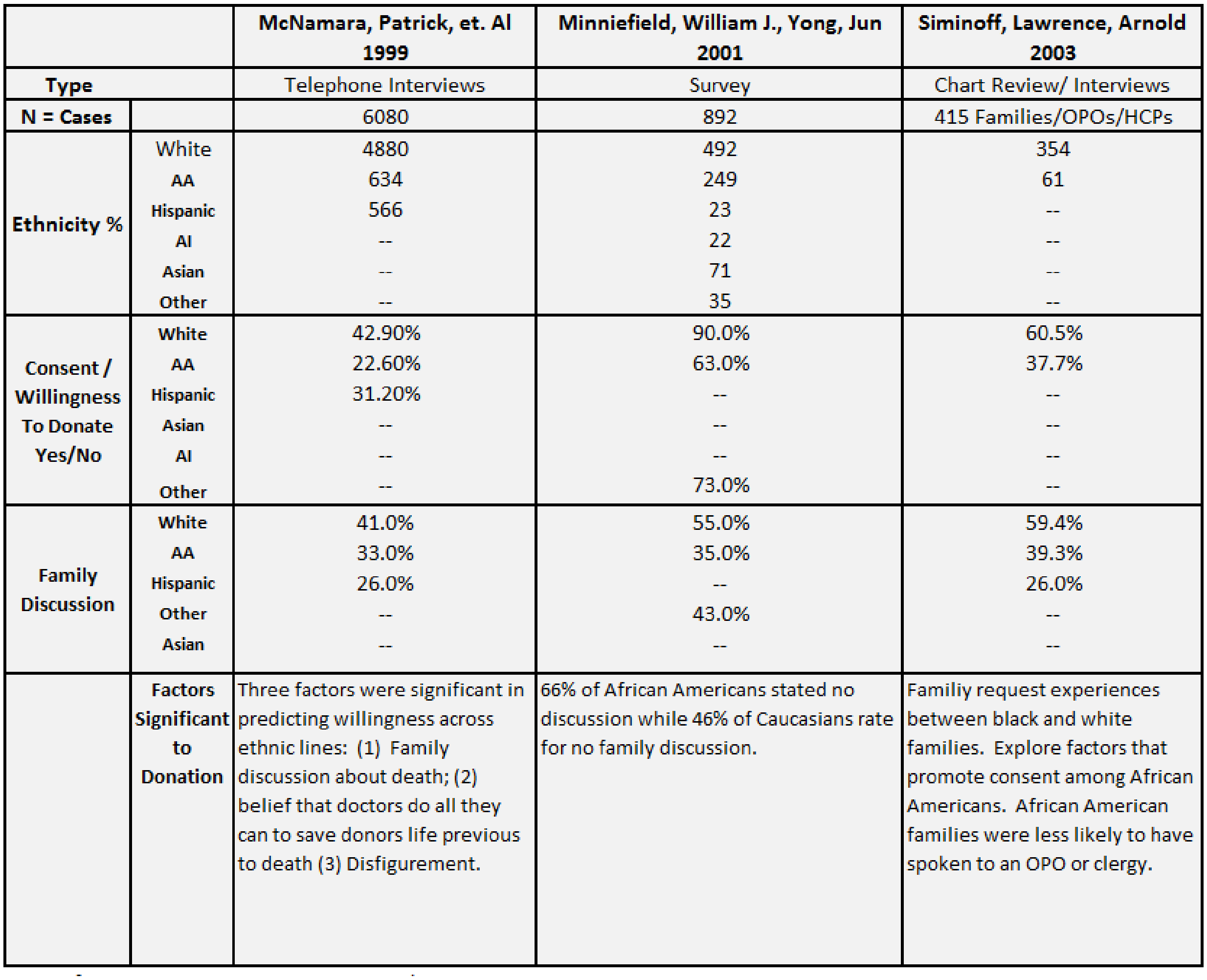
Caucasian families (4.53 vs 7.13; p<.01). These results were very similar across all three studies.

Knowledge is a substantial predictor of willingness toward designating for organ donation. Individuals who have perceived misconceptions about donation are less likely to donate (S. E. Morgan & J. K. Miller, 2002). Individual attitudes toward organ donation also correlates with intentions toward designation for organ donation. Despite these factors, they do little in promoting conversation and discussion about organ donation among family members. However, there was a significant relationship between the individual's level of altruism and willingness in discussing organ donation with family members (r(797) = 0.32, p < 0.001) (S. E. Morgan & J. K. Miller, 2002).

Awareness of organ donation was high across all ethnicities' in Minniefield et al. (2001). However, Caucasians had more access to information regarding organ donation. Willingness was higher in Caucasians than African Americans (80% vs 63%). Family discussion among African Americans was 35% compared to Caucasians at 55%, with a higher prevalence in both ethnicities for women, as shown in Table 7. As in other studies, the lack in trust in doctors and the medical system among African Americans was a major barrier.

McNamara et al. (1999) showed willingness among African Americans who work in healthcare were significantly less likely in showing willingness to donate than those who declined. However, Caucasians and Hispanics who had exposure were more likely in showing willingness toward donation (Caucasians 60%; Hispanics 46%; Africans Americans 43%). Ultimately, Table 7 shows willingness was closely related to previous discussion among all ethnic groups in all three studies.

Table 7. Organ Donation, Family Willingness and Discussion



		McNamara, Patrick, et. Al 1999	Minniefield, William J., Yong, Jun 2001	Siminoff, Lawrence, Arnold 2003
Type		Telephone Interviews	Survey	Chart Review/ Interviews
N = Cases		6080	892	415 Families/OPOs/HCPs
Ethnicity %	White	4880	492	354
	AA	634	249	61
	Hispanic	566	23	--
	AI	--	22	--
	Asian	--	71	--
	Other	--	35	--
Consent / Willingness To Donate Yes/No	White	42.90%	90.0%	60.5%
	AA	22.60%	63.0%	37.7%
	Hispanic	31.20%	--	--
	Asian	--	--	--
	AI	--	--	--
	Other	--	73.0%	--
Family Discussion	White	41.0%	55.0%	59.4%
	AA	33.0%	35.0%	39.3%
	Hispanic	26.0%	--	26.0%
	Other	--	43.0%	--
	Asian	--	--	--
	Factors Significant to Donation	Three factors were significant in predicting willingness across ethnic lines: (1) Family discussion about death; (2) belief that doctors do all they can to save donors life previous to death (3) Disfigurement.	66% of African Americans stated no discussion while 46% of Caucasians rate for no family discussion.	Familiy request experiences between black and white families. Explore factors that promote consent among African Americans. African American families were less likely to have spoken to an OPO or clergy.

(McNamara et al., 1999), (Minniefield et al., 2001), (L. A. Siminoff et al., 2003)

Prior Exposure to Organ Donation

Four studies showed significantly better outcomes toward designation when prior exposure was present toward individual experiences with organ donation. Prior exposure to organ donation creates contemplation and educational experiences for future decisions in organ donation. These studies showed the contrast across ethnicities regarding donation in minority populations. McNamara et al. (1999) entailed 6080 respondents, stratified by ethnicity; with 4880 Caucasians, 634 African American, and 566 Hispanic participants. Results showed 60% of Caucasians vs. 43% of African-Americans and 46% of Hispanics had previous access to donation information previous to the survey. However, access to this type of information is important for discussion to take place. Caucasians were more prone to discussing death arrangements with other family members than minorities at a rate of 41%; while African Americans were at 33%; and Hispanics at 26%. When asked if doctors do all they can to save a life before pursuing donation, respondents answered positively for 92% of Caucasians; 81% of African Americans and 88% of Hispanics. Knowledge on the meaning of brain death results showed Caucasians at 66%, African Americans at 55% and Hispanics at 56%.

Rodrigue, Cornell, and Howard (2009) cited the fact that its respondents, which were 63% consenting next of kin considered their most important source of information was the 6 months previous to family member’s death. These most important sources were newspaper/magazine articles at 52.6%; discussion with a family member at 39.6%; public service announcements on TV or radio at 36.1%; movie or TV show at 32.3%; and information from health care providers at 30.9%. Despite the fact that these channels of exposure are available to most people, results showed Caucasian adults were more likely to have been exposed any organ donation (89.6% vs 71.9% $p < 0.001$). Caucasians and the more highly educated tended to have more exposure in the 6 months previous to the death of a loved one.

Exposure to donation information is associated with designating and sharing donation intentions with others. As well, this association is very positive with each increment of donation information exposure (Rodrigue et al., 2009). Many individuals who decline registering have no previous experience with donation or transplantation, have no knowledge of what brain death is, or are in opposition of coming in contact with a deceased body. According to Conesa et al. (2003); (McDonald et al., 2007), these populations tend to rely on religious motivations to decline donation. Transplant education, knowledge of donation and transplantation, and religious beliefs have shown to be related directly to positive results toward organ donation (S. E. Morgan, 2006; Rumsey, Hurford, & Cole, 2003).

Education Programs

Deedat, Kenten, and Morgan (2013) presented 18 significant organ donation education studies exploring effective interventions, of which 17 were prevalent to this study are listed in Table 8. These studies consist of educational interventions which include mass media, point-of-decision and interpersonal interventions. These studies represent some of the best possible studies available to determine effectiveness of donation education programs amongst various minorities. And finally, intervention characteristics were examined based on outcome.

Accuracy in information about organ donation and transplant is detrimental towards increasing organ donation participation among all populations. Misinformation and misconceptions are dangerous for a subject that has the potential of being extremely uncomfortable for discussion. Increasing accurate knowledge about organ donation and transplantation is especially important for minorities who lag behind in donation rates.

The lack of information available regarding organ donation has been at a cost for many patients and families. Individuals and families reported having very little contact or access to organ donation information apart from passive information provided by the Department of Motor Vehicles (Long et al., 2012). Table 8 contains six educational studies which specifically target minority populations, behavior, and attitudes needed in considering designation.

Culturally accurate information in minority communities is of critical need as the donation rate must be increased in order to save lives. Modifiable barriers such as lack of knowledge and access can be decreased significantly by educational interventions. Additionally, education provides a way to address barriers such as perceived cultural and religious beliefs that have no grounding in facts; as well, address the lack of trust in minority communities (Deedat et al., 2013).

Although mass media has the ability to reach many people, it has not necessarily been effective in minority populations in respect to creating willingness toward organ donation registration as mentioned earlier (S. E. Morgan, 2006; Rodrigue et al., 2009). Community-based campaigns are more effective at promoting minority family conversation and also provides other positive outcomes as well (S.E. Morgan, 2004). However, educational interventions combined with mass media have shown to be much more effective in increasing designations for donation (Deedat et al., 2013; S.E. Morgan, 2004). Educational interventions can also be very effective in getting immediate results by taking advantage of one-on-one proximity designation to allow donors to designate immediately.

Deedat et al. (2013) cited several studies unique in educating minorities in organ donation education. A study conducted among 1580 American Indians from the Northern Plains reviewed print materials and videos with a before and after component issued by an outreach coordinator. The test was designed with the help of key stakeholders in the community as well as academic researchers. The Transtheoretical Model was used to measure effectiveness of any pre and post-test stages of change. Pre-test results showed respondents whom had not contemplated organ designation at a baseline of 55% and those who had contemplated organ donation at 45% of respondents. After the intervention was established and post-test were completed, results showed 43.1% of respondents stayed at the same stage and 56.9% progressed to the stage of motivational readiness (SMR). In total, 26.5% changed to contemplation stage, 19.4% changed to preparation stage (designated to be donors), and 11.1 % achieved discussing decision with their families. Changes in donor intent were considered significant based on progression of 18.32, $p<0.05$ (Deedat et al., 2013).

A larger study conducted by Harrison, Morgan, King, and Williams (2011) combined a threefold intervention using mass media; point-of-decision and interpersonal components. This study consisted of 771 African Americans and Caucasians. Mass media and point-of-decision were created to stimulate and increase association between the belief and the behavior of designating for organ donation. Interpersonal components consisted of interpersonal communication and health campaigns. Interpersonal interventions have been known for being more effective in increasing knowledge, attitudes, norms, intentions, and behaviors toward organ donation (Harrison et al., 2011). This intervention showed significance in sign-ups among African Americans with an increase of 700% above baseline. The interpersonal components were key in increasing donations in this particular study for both populations. However, African Americans and Caucasians did respond differently during distinctive times and different interventions. It was also very significant that this intervention used mass media to prime participants for more direct interventions at a later period of time in order to achieve such a substantial increase.

Table 8. Overview of Education Studies

Author and Country	Demographics sample size (n)	Study Design	Program Delivery	Results	Outcomes	Theoretical framework
Allen and Stillwater, USA	Alaskan native N=54 Health staff N=<200 students	Before and after	PowerPoint presentation and video focused on issues about OD and Alaskan natives	Improved knowledge and positive attitudes towards donation and intention to register post test	Knowledge and intention to register as a donor	Not mentioned
Alvaro et al, USA	Hispanic	Before and after	On alternate weeks, employees of the local organ procurement organization offered the attendees at a flea market an immediate opportunity to register or information about organ donation	Participants offered an immediate opportunity to register rather than just information about OD were significantly more likely to register (86% vs 54%)	Verified registration	The IFF model (immediate opportunity, information, focused engagement and favorable activation)
Andrews et al, USA	African American intervention n=622 control n=632	Cluster randomization	Members of the congregation undertook discussions with lay health advisors about organ donation. DVD designed to address OD barriers for Africa.	Increase in verified enrollment on donor registry in intervention group. No increase in knowledge observed	Verified enrollment on donor registry	Not mentioned
Callender et al, USA	Multiethnic N=914	Before and after study	Presentation about organ donation delivered by transplant recipients, donors, individuals on transplant lists healthcare professional who are ethnically similar to the target population	Improvement in knowledge and attitudes towards OD, high reporting of willingness to discuss OD with family	Willingness to donate organs for oneself and loved ones after death. No valid measures to assess attitudes to OD	Not mentioned
Thornton et al, USA	Multiethnic Intervention n=443 control n=509	Cluster randomized	5 minute video about organ donation prior to collecting driver's license. Controls obtained license in the usual manner.	Cases more likely to register as donors compared to controls (76% vs 54%)	Verified enrollment on donor registry	Not Mentioned
Fahrenwald et al, USA	American Indians N=1580	Before and after study	Out-reach coordinators facilitate delivery to small groups who were required to read and discuss a 1 page brochure. This was followed by a 13 min video and a group discussion facilitated by the coordinator	Significant change in stage of motivational readiness to become an OD post intervention	Stage of motivational readiness to serve as an organ donor	Transtheoretical model of behavior change
Resnicow et al, USA	African American Intervention n=1370	Cluster randomized	Hair stylists trained as lay health advisors used motivational interviewing to discuss OD with participants.	Participants receiving the intervention were 4 times	Self-reported donation status	Not mentioned

				more likely to join the register than the controls	verified enrollment on state registry	
Salim et al, USA	Hispanic N=341	Before and after study	Presentation about the need for transplant and information about donation lead by a local organ procurement organization	Increase in knowledge perceptions and beliefs. No differences in willingness to discuss donation with family or intent to donate	Change in knowledge and attitude Donation intent	Not mentioned
Cardenas et al, USA	Multiethnic Intervention n=96 Control n=91	Cluster randomized	Transplant surgeons and young recipients gave a presentation followed by a Q&A session and a video	Knowledge increase post intervention was the strongest predictor of positive change in opinion about OD	Knowledge, attitudes and awareness of OD	Not mentioned
Feeley et al, USA	Multiethnic	Before and after study	Peer educators delivered a range of campus-based activities	Increased donor registration	Self-reported registration	Not mentioned
Arriola et al, USA	African American Intervention n=175 Control n=162	Cluster randomized	Video and written materials mailed to participants	Greater readiness to sign a donor card, register through a driver's license or talk to family about wishes in the intervention group.	Readiness to express donation intent through a driver's license, donor card and discussion with family	Transtheoretical model of behavior change
Alvaro et al, USA	Hispanic	Before and after study	On alternate weeks, employees of the local organ procurement organization offered the attendees at a flea market an immediate opportunity to register or information about organ donation	Participants offered an immediate opportunity to register rather than just information about OD were significantly more likely to register (86% vs 54%)	Verified registration	IFF model (immediate opportunity, information, focused engaged and favorable activation)
Frates et al, USA	Hispanic N=4500	Before and after study	Prime time television and radio slots	Year on year increase in Hispanic OD consent rates (overall 10% increase). Increase in knowledge/attitudes	Consent rates from organ procurement organization. No valid measures to assess attitudes to OD	Transtheoretical model
Salim et al, USA	Hispanic N=1052	Before and after study	Prime time television and radio slots	Improved knowledge post campaign when compared to baseline	Awareness, perception and belief about OD	Not mentioned

Radosevich et al, USA	African American N=465	Before and after Study	Media campaign conveyed through television, radio, targeted print media. Donor families and healthcare professionals were interviewed on television and radio	Significant increase in knowledge and attitude about organ donation post campaign. No significant change in intention and willingness to become a donor.	Self-reported registration change in knowledge, attitudes and willingness to become a donor	Theory of Reasoned Action
Media and education						
Harrison et al, USA	African American n-626 771	Before and after study	Billboards in the vicinity of vehicle licensing offices and radio adverts. Trained volunteers with links to donation at vehicle licensing offices to engage in conversation	Overall 700% increase above baseline in sign up to the donor register. The magnitude of the increase was greatest when one-to-one promotion was combined with other medium	Verified registration	Communication Design
Hebert et al, USA	Chinese American N=1134	Before and after study	Media campaign Grass roots community outreach	Significant increase in stated intention to donate in the intervention area vs the control area	Joining a donor registry. Express a desire to become an organ donor. Communicating wishes to family	Not mentioned

Deedat, S., Kenten, C., & Morgan, M. (2013)

Communication and Discussion Amongst Family / Next of Kin

As mentioned previously, having prior access to organ donation reduces misconception about the process of donation and transplantation. Six studies were reviewed showing factors of communication essential to organ donation. It creates a positive predictor of good outcomes toward organ donation. However, willingness has to be present for discussion to take place. S.E. Morgan (2004) measured willingness using 3 measures for which a point system was established. These 3 measures were “I would be comfortable talking to my family about becoming an organ donor,”,” I know how to talk to my family about my decision to be (or not to be) an organ donor,” and “I am willing to talk to my family about my decision to be (or not to be) an organ donor,” and “I am willing to talk to my family about my decision to become an organ donor.”

Next of kin are more than likely positive toward organ donation in over 90% of cases where family members have indicated the decision before death (S. E. Morgan & J. K. Miller, 2002). However, there was a lack of information outlets to help motivate these conversations. When asked how they received information or heard about organ donation events, respondents answered; “I don’t know, I see it on commercials. I seen it on a movie. John Q.”; or “One time I read about it in a magazine. I think it was … what magazine was it?” “It was a sports magazine about Alonzo Mourning when he came up with a kidney, kidney failure and he needed a kidney donation” (Long et al., 2012).

Reliance on the media to disseminate accurate and consistent information is problematic because it varies somewhere between accuracy and perception. The examples given show how a true story and information retrieved from a movie can lead to indifference about organ donation. Moreover, the media tends to be the main or only source of information about organ donation that many people ever receive before making the decision to designate for donation (Long et al., 2012).

According to Korda et al. (2007), women were more likely than men to express their decision to donate through discussion. Twenty-seven percent of all participants expressed their decision by more formal means such as an organ donor card or driver's license. Any respondent which took the more formal route was 14.4 times more likely to have discussed their decision. Purnell et al. (2011) itemized disclosure preferences through personal and public disclose methods by asking respondents what preferences they preferred for designation methods. Table 9 summarizes Purnell's top personal and public preferences for disclosure.

Table 9. Disclosure Preferences (Personal & Public)

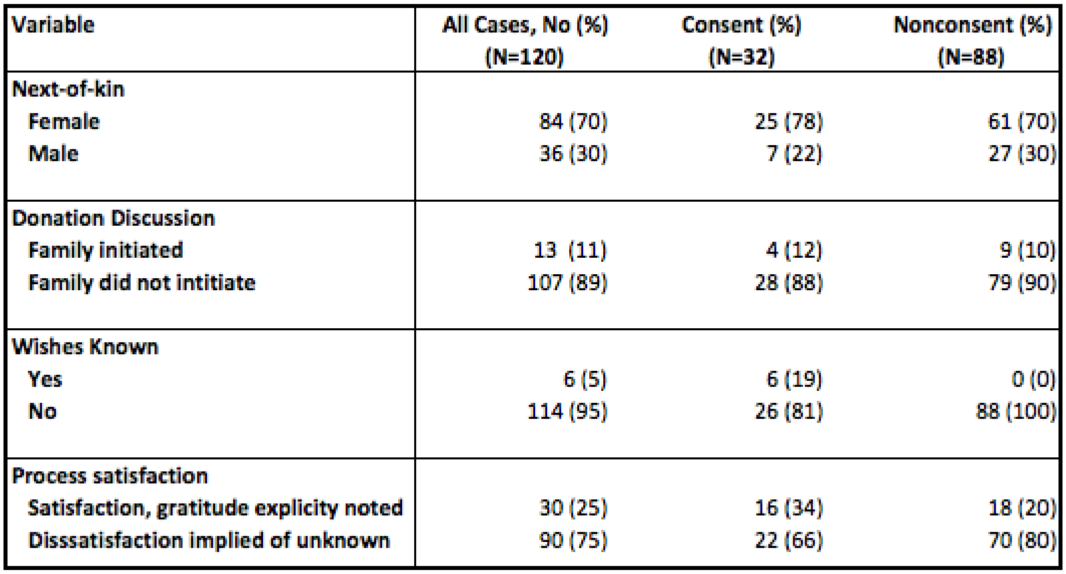
Personal Discussion	Public Registration
Family Members	Mail, telephone, computer
Physician	Workplace
Pastor, rabbi, other religious representative	Place of religious worship
	Grocery store, bank, post office

Purnell et al. (2011)

Similarly, Minniefield et al. (2001) tried to realize differences in willingness for African Americans vs Caucasians and other ethnicities. This 12-question survey was administered to 249 African Americans vs. 492 Caucasians, 23 Hispanics, 71 Asians, and 22 American Indians and the difference in attitude toward organ donation. Thirty-eight percent of African Americans vs. 10% of Caucasians said they would not designate for donation. In regards to family discussion, 66% of African American respondents stated there was no discussion at all and Caucasians were at 46% when stating there was no family discussion.

Dodd-McCue and Tartaglia (2007) showed the impact of families having knowledge of donor wishes showed significantly more in consent cases. Like previous studies, women were the dominant decision makers in 78% of all nonconsent cases. But more importantly, donor wishes were known in 19% of consent cases and donor wishes were known in none of the nonconsent cases p = .000. Table 10 shows a summary among consent and nonconsent respondents.

Table 10. Overview of African American Consent and Non-Consent



Variable	All Cases, No (%) (N=120)	Consent (%) (N=32)	Nonconsent (%) (N=88)
Next-of-kin			
Female	84 (70)	25 (78)	61 (70)
Male	36 (30)	7 (22)	27 (30)
Donation Discussion			
Family initiated	13 (11)	4 (12)	9 (10)
Family did not intitiate	107 (89)	28 (88)	79 (90)
Wishes Known			
Yes	6 (5)	6 (19)	0 (0)
No	114 (95)	26 (81)	88 (100)
Process satisfaction			
Satisfaction, gratitude explicity noted	30 (25)	16 (34)	18 (20)
Disssatisfaction implied of unknown	90 (75)	22 (66)	70 (80)

Dodd-McCue, D., & Tartaglia, A. (2007)

Summary

Willingness and attitude toward organ donation and the actual act of donation can be tied to various characteristics and experiences of individuals. Gender as well as ethnicity constantly showed significant differences in patterns of registration designations. Although many people agree that organ donation is good for society, results show actual designations are much lower. Barriers such as religion, distrust, premature death, understanding brain death remain dominate barriers of organ donation. Controllable barriers such as exposure, education have shown to be excellent interventions to organ donation in minority populations.

Chapter 5 – Discussion

Introduction

The purpose of this systematic review was to explore the simple but complicated act of family discussion of organ donation among minorities in the US. Data were gathered from multiple organ donation studies related to significance of family communication in regards to attitude and willingness toward designating for organ donation and transplantation among minorities in the US. The single biggest reason many potential transplants never take place is due to the lack of discussion among family members. This failure of communicating and planning forces grieving family members to make these important decisions while struggling with the death of a loved one. The solution to correcting these critical issues of organ donation shortages are multifaceted and interrelated in changing attitudes, behaviors, and social norms of various minority populations throughout the US. Having these discussions undoubtedly shows improved outcomes considerably across the spectrum of all ethnicities, however this study focused on minorities willingness. This lack of communication in family donation requires more research, intervention, and education by decreasing barriers, and increasing interventions related to education and research.

Key Study Findings

Despite years of research and intervention, organ donation and transplantation are stifled by the lack of donated organs. Many transplants do not occur due to the lack of participation from minority populations failure to designate, therefore many people continue to die waiting for organ transplants. Articles gathered for this study explored the reasons for these shortages and numerous authors cited barriers in minority populations that continue to contribute to these deficits. These studies were also able to cross reference barriers by relating them to ethnicities, age, educational and income status. Additionally, numerous authors show donors whom have designated to become donors are sometimes declined because of communication breakdowns between the donor and family members due to one or more barriers.

Articles related to this study used quantitative and qualitative results showing how barriers continue to exist and how many if resolved, lead to increased donation rates. Findings of core studies show simple communication and discussion assist in getting past barriers and taboos that affect organ donation in a negative way. Although many barriers cannot be terminated immediately, studies show providing exposure helps in building contemplation and intention toward organ donation.

Barriers such as distrust, religious objections, premature death, social norms and ambiguous definition of brain death have lingered in minority populations for some time. Little has improved over the last 20 years in community or individual communication. According to the research, barriers that cause many to hesitate from designating are a major contributor for family members' decision to override donor wishes to donate because the potential donor never shared their wishes or had discussions with their families.

Factors related to determining whether an individual may become a donor are closely related to demographics such as education, age, and ethnicity. Additionally, willingness and attitude must be included to instill change of decision to perform some type of family discussion. Trust that doctors do all they can to save a life before considering donation; and this must be clear to family and loved ones. Moreover, the family must be at peace with the fact that donation will not cause disfigurement.

Organ donation literature over the past 20 years has shown as much as 60% of the US population is favorable toward organ donation. However, the actual act of donating is much less, specifically in minority populations. The 2012 National Survey described the demographics of populations that require willingness factors to be in place in order for individuals and families to move forward and feel comfortable with designating for donation.

Factors related to positive results in organ donation are important for the act of donation to occur. Awareness of the process of donation is very effective toward healthy discussions about transplantation. Furthermore, awareness is also very beneficial in dispelling myths and taboos, and cultural norms that are not necessarily rooted in facts (S. E. Morgan, 2006).

Bivariate correlations were performed on variables such as social norms, religion and willingness, which showed the significant effect of these factors. Core studies found social norms influence in forming attitudes about organ donation. Despite barriers that exist, particular factors must be present in order for organ designation to occur. Disfigurement must not be a concern in order to gain approval from family members. These concerns have led to as much 57% to 79% declination of African American and Hispanic participating in the organ donation process (Verble & Worth, 2012).

Trust is a major factor in creating and maintaining willingness to designate. Although, research has shown mistrust is highly significant, it is usually not grounded in facts, but more likely perception. Additionally, many individuals have shown preference to revealing donation to alternative representatives such as their physician at rates as high as 65%.

Willingness toward discussion was very similar as other factors in showing lower rates of participation among minority populations. Minorities were less likely to believe doctors and hospitals would do everything they could to save their lives than Caucasians. Minority families were also less likely than Caucasians to know their loved one's wishes by a difference of 24%.

The stages of contemplation assist in moving individuals toward the final step of registering for organ donation. However, this act often requires an individual have access to donation information previous to the final decision. This process includes discussing death arrangements, which gives next of kin the confidence they need to make donation decisions if an organ donation opportunity presents itself.

Accuracy in donation education is important in delivering facts and separating them from the perceptions left by assumptions and ideals taken from the media about organ donation. Lack of information and passive information from locations such as DMV are not adequate for organ donation education. Educational programs are more effective when combined for effectiveness. Mass media, point-of-decision, and interpersonal components applied in stages have shown significant success in increasing designation rates.

Research is vital in increasing willingness to communicate among populations to explore how positive decisions to donate organs occur (S.E. Morgan, 2004). Techniques in measuring willingness are vital for research to continue. S.E. Morgan (2004) used Likert scale of qualitative measures to enable individuals to answer questions about how individuals discuss designation for donation, willingness to talk, knowledge and prior discussion.

Next of kin are more positive where decisions have been made prior to death of a donor. As many as 90% of cases have shown positive results from donation where discussion and decisions were made prior to death and donation (S. E. Morgan & J. Miller, 2002). Lack of sources to stimulate conversation remains an obstacle. These resources are helpful in dispelling barriers such as media broadcast inaccuracy information that contributes to false beliefs about organ donation. Finally, effective interventions need to be matched in the direction of the population’s stage of readiness for registering. Measured outcomes should include registration and shifts along the pathway towards this behavioral outcome (Deedat et al., 2013).

Limitations

There was little to no significance taken into account regarding religious backgrounds and spiritually in most studies when selecting participants. Many studies had an imbalance of ethnicities that were managed by proportion. Additionally, there was a tendency for populations to be centralized in areas such as schools, churches, civic organizations, and cities that may have their own bias, therefore the possibility of bias exist in respect to representativeness. Some studies had an imbalance of education among respondents, for which some were intentional, which is very crucial toward outcomes of organ donation. As well, study participants had different levels of knowledge of organ donation and transplantation. Therefore, some opinions and decisions were made based on that level of education which may not have been intentional.

Several studies stated that they were more likely to talk with a donor family than nondonor families. Since nondonor families tend to be minorities, some studies could be somewhat unbalanced. As well, many facts from HCPs were based on recollection of previous experiences. Many family recollections were discussions with donor, so there was no way to confirm accuracy of some data.

Much of the data is self-reported from respondents of the sensitive matter of organ donation. Therefore, some respondents may have answered in a way they felt is acceptable by their culture or society, as opposed to answering their own true opinions. Some selection bias may have occurred simply because some individuals have interest in talking about organ donation as opposed to some who have no interest or negative interest in organ donation.

S.E. Morgan (2004) revealed the fact that it was not clear if respondents had not gotten around to signing donor cards after having discussions with donor cards, or if a family member had influenced respondent to designate for organ donation.

Little or no analysis was reported on subjects such as “taboo” and “jinx” which are based in silence and avoidance of discussing death or deceased bodies. Two authors touched on the subject, but there was no analysis, nor were the its origins and how in depth its influences have in today’s populations.

This research was limited to secondary exploratory data. A variety of methods were used to analyze the data. There was no way to investigate areas where more research was warranted due to lack of some questionable data.

Implications

This research is a collection of studies that assist in building further progress of organ donation and the gap that exists with availability of organs. The act of discussion is important for difficult matters such as death and organ donation. This research has the ability connect various factors related to the willingness, and act of designating for organ donation. The research offered by this study emphasized major barriers of factors required to promote communication among family members. These synthesized studies recognized how these acts of silence are cultural and the difficulty in researching (S.E. Morgan, 2004).

This secondary research indicates there is an acute need for ethnically specific organ donation interventions and education to improve the deficit of access and knowledge of organ donation and transplantation in minority communities. The research has also pointed to the need to correct misinformation which is spread primarily through print media, television, and news.

Recommendations

Research

Researching minority families' attitude, behavior and the lack of communication in regards to death is critical. Taboo conversations about death, "jinx", and "ick" factors were only lightly mentioned in three studies. A better understanding of barriers may help education providers in customizing community and ethnically based materials to help define fears from cultural norms. Discussion and planning are critically important for designation in several aspects such as enabling families to be more prepared for unknown family medical events. Additionally, decisions are made with a larger degree of confidence for family members, when discussion takes place.

Research in the area of religious doctrine and its relationship to barriers are necessary in separating declinations based on religious beliefs, body disfigurement, and dying without all organs intact. Finding the origins of such beliefs may help to bring about more discussions about subjects that many have learned to avoid from an early age.

Education

Efforts to increase organ donation in the US have been slow in minority communities. Education in a unique ethnically centered format customized for minority communities is necessary toward providing awareness. The education being provided currently is not being received by significant minority segments of the population. A more culturally defined intervention for ethnic communities will help in giving more awareness to those who rarely come in contact with the subject of organ donation and transplantation.

Organ donation crosses several fields of practice such as social and behavioral science, medicine, and public health. Future interventions should involve social and behavioral research in professions such as community mentors, hospital improvement specialists, and organ donation advocates (Siegel, 2009). When confronting the issues of organ donation, it is important to concentrate on population needs, and what barriers are significant in each minority community. For instance, many African American and American Indian cultures perceive discussing death a taboo and never discuss death in fear of creating “jinx” or bad luck (S. E. Morgan & J. K. Miller, 2002). Customized interventions that work, can be duplicated for specific communities according to the needs of the community, culture, and social norms.

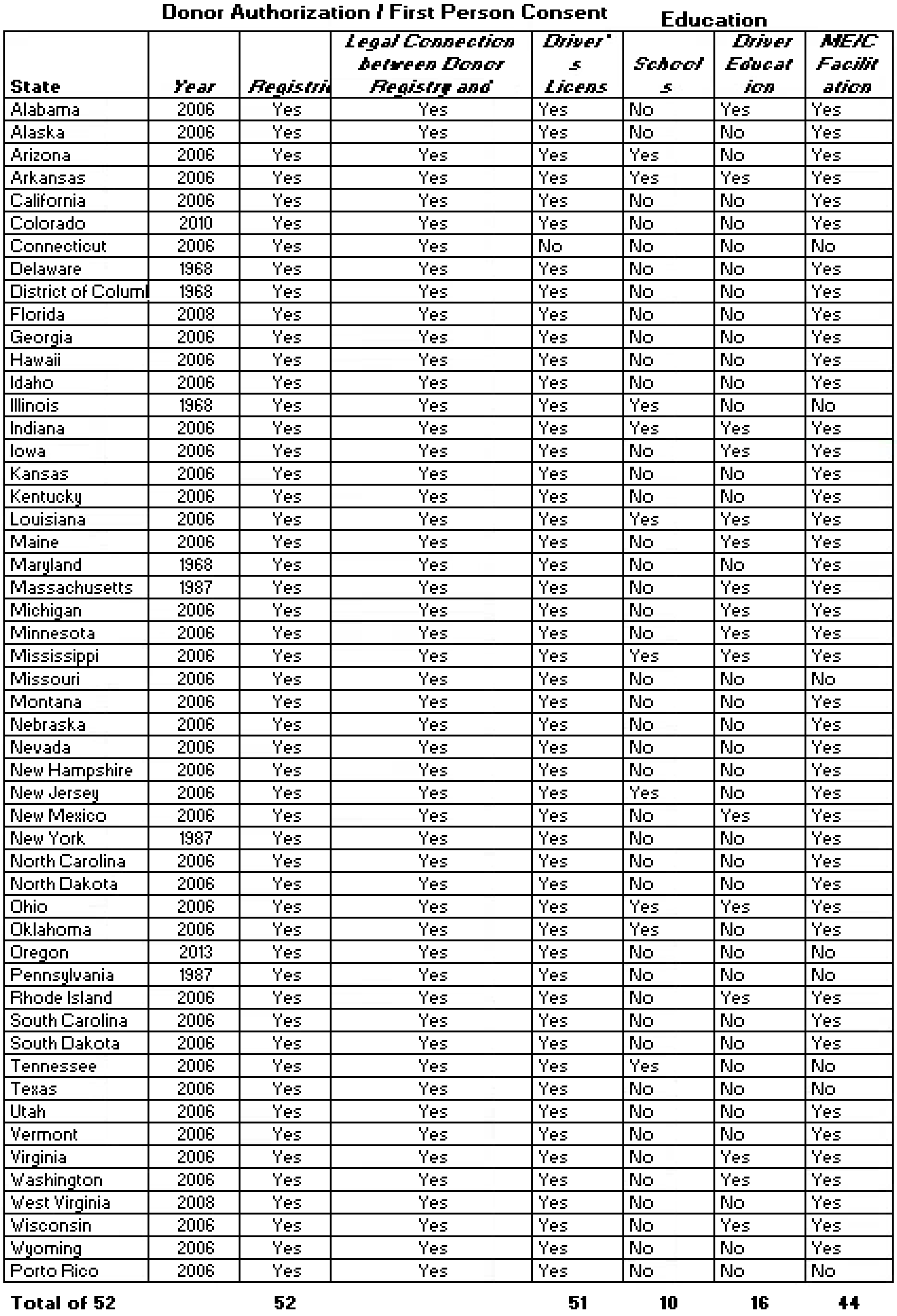
Conclusion

There is a lack of research in the area of attitude and willingness to communicate about the act of altruism toward organ donation in non-Caucasian populations. This lack of increased registrations has caused a decrease in the donation/transplantation process due to barriers that are difficult to reverse. Almost half of these barriers are the issue of next of kin not being aware of a donor’s choice to donate after death. These barriers were explored in detail, as well as factors that create more positive attitudes and willingness toward intentions to donate. Encouraging family discussion in communities that harbor negative attitudes is detrimental because it is so deeply rooted. It is especially difficult because these behaviors linger with no clear reason of where they come from or why they exist.

It is critical that family members know the wishes of their loved ones for organ donation and transplantation to increase participation. When next of kin know the wishes of loved ones, the consent rate is increased and next of kin feel better about their decision.

This study was able to synthesize many results and studies that help in understanding the many factors involved in how and why some populations donate more or less than others. The connection between attitude, willingness, awareness and knowledge were very important in bringing individuals from stages of negativity toward points of willingness to be organ donors. It also showed how critical educational interventions are to overcoming this critical issue. Revisiting all barriers and creating more interventions and in-depth educational programs is necessary for minority families to understand the effects of behaviors and attitudes.

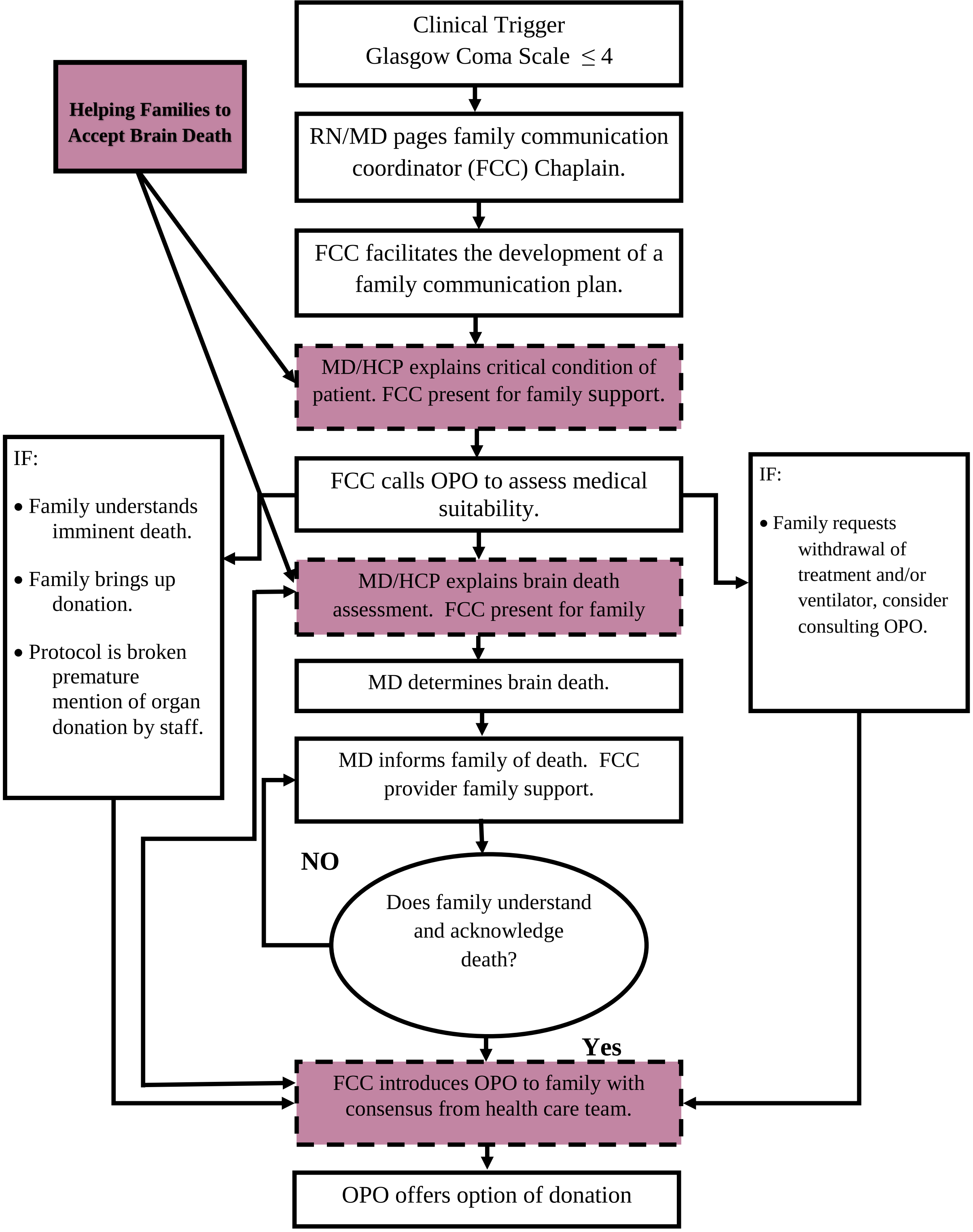
Appendix A. First Person Consent and Education by State



		Donor Authorization / First Person Consent			Education		
State	Year	Registri	Legal Connection between Donor Registry and	Driver's Licens	Schools	Driver Education	ME/C Facilitation
Alabama	2006	Yes	Yes	Yes	No	Yes	Yes
Alaska	2006	Yes	Yes	Yes	No	No	Yes
Arizona	2006	Yes	Yes	Yes	Yes	No	Yes
Arkansas	2006	Yes	Yes	Yes	Yes	Yes	Yes
California	2006	Yes	Yes	Yes	No	No	Yes
Colorado	2010	Yes	Yes	Yes	No	No	Yes
Connecticut	2006	Yes	Yes	No	No	No	No
Delaware	1968	Yes	Yes	Yes	No	No	Yes
District of Colum	1968	Yes	Yes	Yes	No	No	Yes
Florida	2008	Yes	Yes	Yes	No	No	Yes
Georgia	2006	Yes	Yes	Yes	No	No	Yes
Hawaii	2006	Yes	Yes	Yes	No	No	Yes
Idaho	2006	Yes	Yes	Yes	No	No	Yes
Illinois	1968	Yes	Yes	Yes	Yes	No	No
Indiana	2006	Yes	Yes	Yes	Yes	Yes	Yes
Iowa	2006	Yes	Yes	Yes	No	Yes	Yes
Kansas	2006	Yes	Yes	Yes	No	No	Yes
Kentucky	2006	Yes	Yes	Yes	No	No	Yes
Louisiana	2006	Yes	Yes	Yes	Yes	Yes	Yes
Maine	2006	Yes	Yes	Yes	No	Yes	Yes
Maryland	1968	Yes	Yes	Yes	No	No	Yes
Massachusetts	1987	Yes	Yes	Yes	No	Yes	Yes
Michigan	2006	Yes	Yes	Yes	No	Yes	Yes
Minnesota	2006	Yes	Yes	Yes	No	Yes	Yes
Mississippi	2006	Yes	Yes	Yes	Yes	Yes	Yes
Missouri	2006	Yes	Yes	Yes	No	No	No
Montana	2006	Yes	Yes	Yes	No	No	Yes
Nebraska	2006	Yes	Yes	Yes	No	No	Yes
Nevada	2006	Yes	Yes	Yes	No	No	Yes
New Hampshire	2006	Yes	Yes	Yes	No	No	Yes
New Jersey	2006	Yes	Yes	Yes	Yes	No	Yes
New Mexico	2006	Yes	Yes	Yes	No	Yes	Yes
New York	1987	Yes	Yes	Yes	No	No	Yes
North Carolina	2006	Yes	Yes	Yes	No	No	Yes
North Dakota	2006	Yes	Yes	Yes	No	No	Yes
Ohio	2006	Yes	Yes	Yes	Yes	Yes	Yes
Oklahoma	2006	Yes	Yes	Yes	Yes	No	Yes
Oregon	2013	Yes	Yes	Yes	No	No	No
Pennsylvania	1987	Yes	Yes	Yes	No	No	No
Rhode Island	2006	Yes	Yes	Yes	No	Yes	Yes
South Carolina	2006	Yes	Yes	Yes	No	No	Yes
South Dakota	2006	Yes	Yes	Yes	No	No	Yes
Tennessee	2006	Yes	Yes	Yes	Yes	No	No
Texas	2006	Yes	Yes	Yes	No	No	No
Utah	2006	Yes	Yes	Yes	No	No	Yes
Vermont	2006	Yes	Yes	Yes	No	No	Yes
Virginia	2006	Yes	Yes	Yes	No	Yes	Yes
Washington	2006	Yes	Yes	Yes	No	Yes	Yes
West Virginia	2008	Yes	Yes	Yes	No	No	Yes
Wisconsin	2006	Yes	Yes	Yes	No	Yes	Yes
Wyoming	2006	Yes	Yes	Yes	No	No	Yes
Porto Rico	2006	Yes	Yes	Yes	No	No	No
Total of 52		**52**		**51**	**10**	**16**	**44**

www.organdonor.gov/legislation

Appendix B. Family Communication Protocol



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Appendix C. Population Distribution by State/Ethnicity/Waiting List

Location	Caucasian / 2014	African American / 2014	Hispanic / 2014	Asian / 2014	Indian/Alaska Native / 2014	Two or More Races / 2014	Organ Waiting List, 8/4/2016
United States	0.62	0.12	0.18	0.06	0.01	0.02	
Alabama	0.66	0.27	0.04	0.02	N/A	0.01	0.024
Alaska	0.57	0.02	0.09	0.1	0.16	0.07	n/a
Arizona	0.49	0.04	0.39	0.04	0.03	0.01	0.018
Arkansas	0.72	0.16	0.07	N/A	0.01	0.02	0.002
California	0.39	0.05	0.38	0.15	0.01	0.02	0.177
Colorado	0.7	0.04	0.21	0.02	N/A	0.02	0.020
Connecticut	0.71	0.09	0.13	0.06	N/A	0.01	0.011
Delaware	0.63	0.2	0.1	0.04	N/A	0.02	0.002
District of Columbia	0.37	0.47	0.11	0.04	N/A	0.02	0.013
Florida	0.55	0.16	0.25	0.03	N/A	0.01	0.043
Georgia	0.53	0.31	0.1	0.04	N/A	0.02	0.043
Hawaii	0.19	0.02	0.09	0.53	N/A	0.17	0.003
Idaho	0.82	0.01	0.13	0.01	N/A	0.02	No State Program
Illinois	0.64	0.13	0.16	0.06	N/A	0.01	0.037
Indiana	0.78	0.09	0.09	0.03	N/A	0.01	0.011
Iowa	0.88	0.03	0.05	0.03	N/A	N/A	0.005
Kansas	0.75	0.06	0.12	0.04	N/A	0.02	0.004
Kentucky	0.84	0.08	0.04	0.03	N/A	0.01	0.008
Louisiana	0.58	0.31	0.06	0.02	N/A	0.02	0.016
Maine	0.92	0.01	0.01	0.02	N/A	0.03	0.001
Maryland	0.54	0.29	0.08	0.06	N/A	0.03	0.030
Massachusetts	0.72	0.07	0.11	0.08	N/A	0.02	0.027
Michigan	0.75	0.14	0.06	0.03	N/A	0.02	0.028
Minnesota	0.79	0.06	0.06	0.05	N/A	0.02	0.025
Mississippi	0.57	0.37	0.03	N/A	N/A	0.01	0.005
Missouri	0.81	0.12	0.04	0.01	N/A	0.02	0.014
Montana	0.9	0.01	0.03	N/A	0.03	0.02	No State Program
Nebraska	0.79	0.04	0.11	0.03	N/A	0.01	0.003
Nevada	0.5	0.09	0.28	0.09	N/A	0.03	0.001
New Hampshire	0.92	0.01	0.03	0.03	N/A	0.01	0.001
New Jersey	0.58	0.13	0.19	0.09	N/A	0.01	0.020
New Mexico	0.4	0.02	0.43	N/A	0.12	0.01	0.004
New York	0.57	0.13	0.18	0.1	N/A	0.02	0.077
North Carolina	0.62	0.21	0.1	0.03	N/A	0.02	0.023
North Dakota	0.88	0.02	0.03	0.02	0.04	0.01	0.001
Ohio	0.8	0.12	0.03	0.02	N/A	0.03	0.025
Oklahoma	0.68	0.07	0.11	0.02	0.08	0.04	0.006
Oregon	0.76	0.02	0.12	0.06	N/A	0.03	0.006
Pennsylvania	0.77	0.1	0.07	0.03	N/A	0.02	0.063
Rhode Island	0.77	0.06	0.12	0.04	N/A	0.01	0.002
South Carolina	0.64	0.27	0.06	0.01	N/A	0.01	0.008
South Dakota	0.85	0.02	0.02	N/A	0.08	0.02	0.003
Tennessee	0.74	0.17	0.06	0.01	N/A	N/A	0.023
Texas	0.44	0.12	0.38	0.04	0	0.01	0.096
Utah	0.81	0.01	0.12	0.04	N/A	0.01	0.006
Vermont	0.94	0.01	0.01	0.02	N/A	0.02	0.001
Virginia	0.63	0.19	0.08	0.07	N/A	0.02	0.022
Washington	0.7	0.04	0.13	0.08	0.02	0.04	0.016
West Virginia	0.92	0.03	0.01	N/A	N/A	0.02	0.001
Wisconsin	0.82	0.06	0.08	0.02	N/A	0.02	0.019
Wyoming	0.86	0.01	0.09	N/A	0.01	0.02	No State Program

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