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Exploring the Experiences of African Americans Who Have Been Asked to Donate the  
Organs of a Deceased Loved One

by  
Debra Law

DISSERTATION

Submitted in partial satisfaction of the requirements for degree of  
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GRADUATE DIVISION

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Debra Law

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# Exploring the Experiences of African Americans who Have Been Asked to Donate the Organs of a Deceased Loved One

Debra Law

## Abstract

**Background:** African Americans are disproportionately affected by chronic conditions such as diabetes, hypertension, and kidney failure, all of which can lead to organ failure and require a transplant. Although African Americans comprise approximately 13% of the U.S. population, they represent more than 30% of people on the transplant waiting lists. Barriers to cadaveric organ donation in this community have been identified and widely studied in previous research. Within the African American community, the identified barriers to organ donation include medical mistrust, bodily integrity, and religious concerns. These barriers can adversely impact the decision to consent to organ donation when approached.

**Purpose:** This study is being conducted to examine the experiences of African Americans who have been asked to donate the organs of a deceased loved one.

**Method:** An interpretive phenomenological study, N=19 using semi-structured interviews with African Americans over the age of 18. Paradigm cases are developed from the interview transcripts. These paradigm cases are an analytic approach used to demonstrate the experience of being approached to donate organs after the death of a loved one.

**Results:** The analysis of the interviews shows that the decision of African Americans to consent to donating a deceased loved one's organs is informed by relationships. There is meaning in the

relationship with the loved one prior to their passing, even when the surviving loved one is conflicted. Analyzing this meaning gives greater understanding of the decision-making process. Conclusion: The outcome of this research is that narrative analysis of the experiences leads to greater understanding of organ donation decision-making among African Americans.

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## Chapter I: Introduction

For many Americans who suffer from chronic, acute, or congenital organ failure, transplantation is the therapy of choice. Transplantation can not only extend one's life but also improve the quality of life (Morgan et al., 2006). In the United States, the current allocation process for organ transplantation involves placement on a waiting list until a compatible organ becomes available. Genetically compatible matches within one's own ethnic group usually have greater success. Chronic conditions such as diabetes, hypertension, and renal disease plague a disproportionate number of African Americans. These conditions can lead to organ failure and require transplantation (Glasgow & Bello, 2006). Although African Americans comprise 12.6% of the U.S. population, they represent 30% of people on the transplant waiting list. Yet only 16% of all deceased donors were African American in 2014 (Organ Donor, 2017). This chapter provides a review and critique of the relevant literature related to African Americans and organ donation. The overall purpose of this review is to describe the current state of knowledge related to this phenomenon and identify current gaps in the literature that could be addressed in future research.

### **Background and Significance**

Twenty percent of all transplant recipients in 2018 were African American (Organ Donor, 2018). As of July 2019, African Americans comprised 28.7% of the 113,000+ people on the organ transplant waiting list. Over 67,000 people (59%) on the waiting list are ethnic minorities. At 83.7%, most people are waiting for a kidney (Organ Donor, 2019). African Americans have higher incidence of end-stage renal disease (ESRD) and diabetes requiring a renal transplant compared with non-African Americans, but are referred for transplant less often (Siminoff, 2006). Consequently, African Americans have longer waits for deceased-donor

kidneys than Whites. Of the 36,528 transplants performed in 2018, 21,167 were kidneys. Of those, 5,556 (26.2%) were to African Americans.

More than 4 out of 5 organ donations come from deceased donors. Approximately 80% of the transplants performed in 2017 involved organs from deceased donors (U.S. Department of Health and Human Services, 2018). As of September 2019, 13 to 14% of deceased donors were African American as compared to 65.7% deceased White donors (Organ Donor, 2019). For African Americans, lack of knowledge, mistrust, and religious concerns are the most commonly identified barriers to organ donation (Kopfman et al., 2002; DuBay et al., 2014; Purnell et al., 2012).

### **Methods**

The integrative review was guided by criteria proposed by Whittemore and Knafl (2005), which include: (a) clear problem identification; (b) search strategies; (c) evaluation of the quality of articles selected; (d) data analysis and synthesis; and (e) presentation. The aim of the integrative review is to explore the body of research related to barriers and facilitators to organ donation in African Americans. CINAHL, PubMed, SCOPUS, Ovid, Medline, Psychinfo, Web of Science, Medline, and Transplant Library databases were searched during the period of January 1991 to December 2017. The same review was updated in February 2022 to include January 2018 to December 2021. Inclusion criteria included studies from the United States and the United Kingdom/European Union. Europe was included because Myfanwy Morgan, an expert in the field of organ donation, transplantation, and ethnicity, has conducted research with people of African descent in London and has identified barriers that may apply to Black Americans/Americans of African descent. Additional criteria included: ethnic minorities over age 18; organ, tissue, or blood donation; inpatient or community settings (college campuses,

churches, etc.). This broad range of donations was selected based on pilot interviews which revealed that the choice to consent to donate or not was independent of specific organs, tissue, or blood.

Qualitative, quantitative, and mixed methods studies were included. Studies involving perception of the meaning of organ donation, the process of organ donation, consent, and donor card registration were included. The search terms “African Americans; Black Americans; Blacks; organ donation; kidney donation; transplantation; barriers; mistrust and religiosity” were used. Inherent in organ and kidney donation were the terms blood and tissue donation. PubMed was searched first as it seems to be the most comprehensive database of references on life sciences and biomedical topics. PubMed yielded 45 articles, all of which were research articles. Also, the database Scopus was utilized. This database was selected because it covers over 20,000 peer-reviewed journals in the scientific, technical, medical and social sciences. Scopus yielded 41 articles and abstracts. A total of 102 citations resulted from all databases. Citations from other sources, such as references from other articles, numbered 30. Of the combined 132 articles, 22 were duplicates, leaving 110. Twenty-four citations were excluded based on the abstract and title. Of the remaining 86 articles, 30 were excluded for relevance and scope.

The updated literature search yielded 6 new papers. These additional papers are reflected in the total number of articles that met the criteria for this review. The updated search was performed in order to insure that the most current and quality literature was represented. The additional 6 articles also demonstrate how the literature has evolved in the additional 4 years.

The remaining 56 articles were appraised using the Mixed Methods Appraisal Tool (MMAT). The MMAT is widely used because it includes quality appraisal criteria for multiple types of research designs, including qualitative, quantitative and mixed method among other

research designs. Ideally, a minimum of two independent appraisers rate the studies based on five criteria. The developers of the tool discourage the reviewers from calculating an overall score from the ratings of each criterion, thus excluding studies with low methodological quality. Instead, reviewers are encouraged to “provide a more detailed presentation of the ratings of each criterion to better inform the quality of the . . . studies” (Hong et al., 2018, p. 1). Based on the developers’ explanations of the methodological quality criteria, I chose to make certain criteria more heavily weighted than others. For example, for quantitative descriptive studies, the MMAT criterion—“Is the sampling strategy relevant to address the research question?”—ranked higher than “Is the risk of nonresponse bias low?” Total scores for each study would not accurately reflect the methodological ranking. Based on the MMAT quality standard, 27 studies were excluded. The final sample of 29 studies were retained for review, analysis, and narrative synthesis (Figure 1).

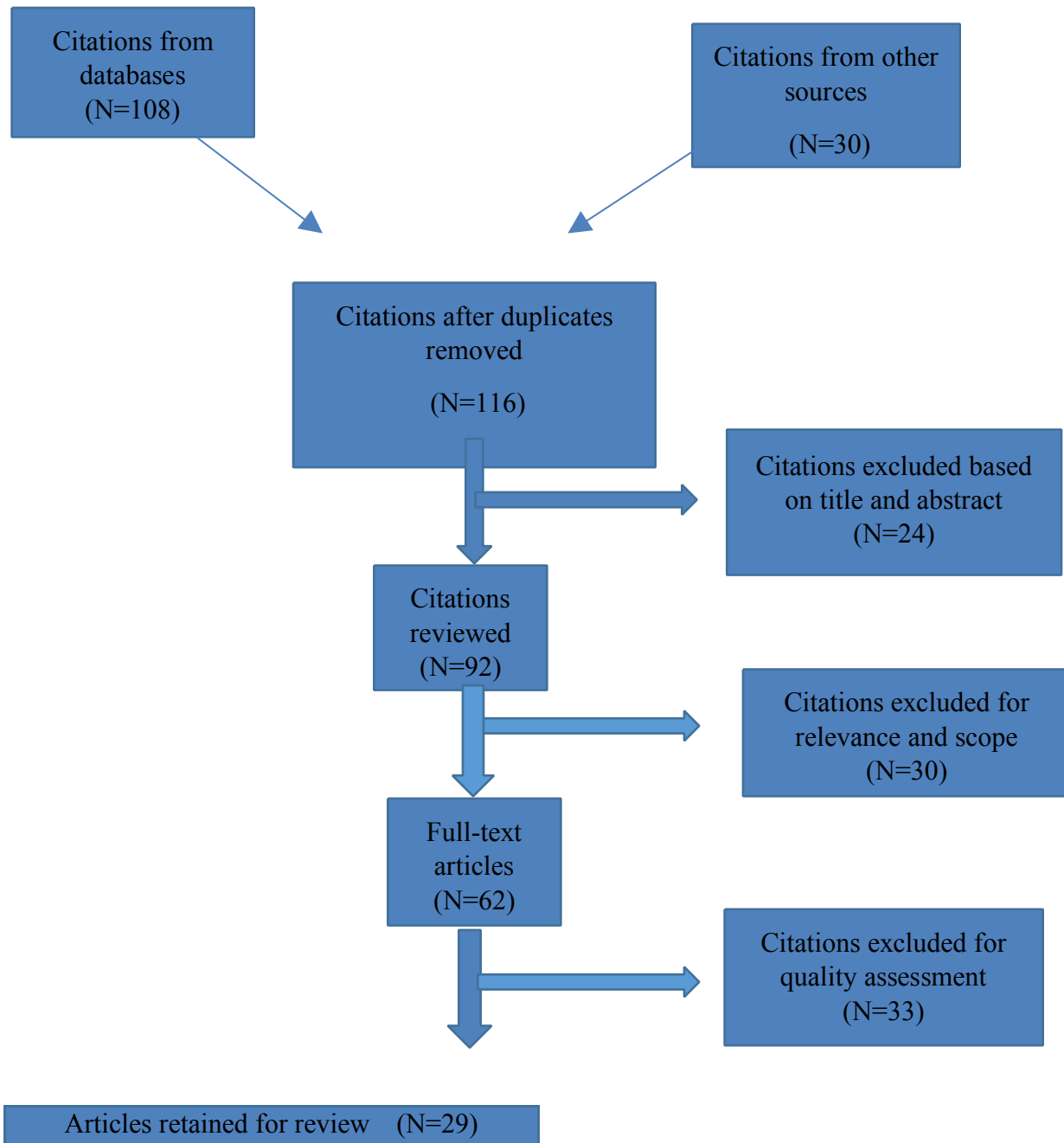


Figure 1.1. Flow Chart Showing Exclusion Process.



## **Findings**

The findings of the literature review are organized into five major sections: (a) lack of knowledge, (b) mistrust, (c) allocation, (d) religion, (e) bodily integrity, (f) misperceptions, (g) donor intention and the role race and class play in this phenomenon. The findings section concludes with a critique of the methodological quality of the studies included in the review.

### **Lack of Knowledge**

Several researchers have addressed the issue of lack of knowledge as it relates to organ donation and African Americans. Lack of knowledge among Blacks (term used interchangeably in the literature) is one of the most commonly studied barriers to donation in the United States, as well as Britain and Europe. Research suggests that knowledge is a predictor of intent to donate (Morgan & Cannon, 2003; Morgan et al., 2008; Rumsey et al., 2003; Spigner et al., 2002; DuBay et al., 2018). The types of knowledge related to (a) the need for organs, (b) the process of transplantation, and (c) knowledge of individuals who have been affected by donation and/or transplantation (Jacob Arriola et al., 2007; Reinhart & Lilly, 2020). Morgan and Cannon (2003) hypothesize that lack of knowledge was a contributing factor in African Americans' lack of willingness to donate organs. They surveyed African Americans in New Jersey (n=310) using a tool which consisted of two sets of knowledge items. The researchers did not specify the contents of the first set of knowledge items other than to say they were "commonly used" in organ donation-related studies. The second set of knowledge items specifically pertained to African Americans: "High rates of hypertension and diabetes among African Americans leads to a higher need for organ donation."

Participants rated family as the leading source (42%) of organ donation-related knowledge. The same researchers also compared those who had signed a donor card (n=124) and

those who had not signed a donor card. Of the participants who signed an organ donor card, 77% answered correctly (i.e., in the affirmative) the knowledge question, “Have you discussed your decision to be/not be an organ donor with your family?” (Morgan & Cannon, 2003). In another study, ethnically diverse students from 3 urban high schools (n=247) completed a culturally sensitive 35-item test. More than 50% of the respondents did not know the correct answers to 13 out of 15 knowledge questions related to organ donation. Television and school were their primary sources of knowledge about organ donation (Spigner et al., 2002).

The process of cadaveric organ transplantation begins with knowing how to become a registered donor, as well as what constitutes brain-death and the determination of donation suitability (Rumsey et al., 2003). A basic understanding of the allocation system is also important (Jacob Arriola et al., 2007). Knowledge of the transplantation process was associated with a more positive attitude toward organ donation among undergraduate students (n=190) attending a small Midwestern university who completed the 20-item questionnaire known as the Organ Donation Attitude Scale (Rumsey et al., 2003). Because family consent is required for cadaveric donation, knowledge of the donor’s wishes accounts for a significant difference between African American consent and nonconsent rates. (Dodd-McCue & Tartaglia, 2007)

Some studies suggest that knowledge is limited among groups of color as donation is perceived as something not practiced in non-White communities (Morgan et al., 2013).

Research by Spigner et al. (2002) indicated that African Americans were more likely to have differences in knowledge about donation as compared with Whites. Personal knowledge of transplant recipients and/or donors plays an important role in African Americans’ donation decision-making (DuBay et al., 2019; Jacob Arriola et al., 2007; Robinson et al., 2014; Terrell Moseley et al., 2004). Seattle, Washington-based researchers surveyed ethnically diverse students from three different high schools in one city. Fourteen percent (n=247), reported knowing someone who had received an organ transplant. Among students who knew a transplant recipient, 23% stated the recipient was of a similar ethnic/racial background as the student (Spigner et al., 2002).

Kopfman et al. (2002) assert that based on their study, African Americans are less likely than Whites to know someone who had indicated intent to donate by signing a donor card. They also found that knowing individuals who have been affected, which is also known as experiential knowledge, is associated with a greater willingness to register as a donor (Jacob Arriola et al., 2008). African Americans who hear about positive transplant outcomes are also more inclined to consider becoming donors (Jacob Arriola et al., 2008; Rumsey et al., 2003; Spigner et al., 2002). Sometimes lack of knowledge regarding the need for organs is a barrier to donation. In one study in which researchers compared the perceptions of African American and White families related to organ donation requests, only 38% of African American respondents (n=61) reported hearing anything about the need for African American donors (Siminoff et al., 2003). Almost 73% of the African American respondents had no explicit knowledge of the wishes of the patient about donation (Siminoff et al., 2003). Slightly more than 3% of African American families in the same study were explicitly informed by the hospital about the need for more Black donors.

### **Mistrust**

Throughout U.S. history, injustices have been perpetrated on vulnerable populations in the name of research. Institutional Review Boards (IRBs) were created to protect the rights of individuals who participate in research. Many years of “medical abuse have created a deep-rooted and well-justified mistrust of physicians and hospitals” among the African American community (Morgan & Cannon, 2003, p. 1067). In response, the Terrell and Terrell Cultural Mistrust Inventory (CMI) was created to measure the level of mistrust African Americans have of Whites (Terrell et al., 2004). When administered as part of a study examining cultural mistrust and organ donation (n=107), the findings revealed that Blacks who mistrust Whites were less willing to consent to either donating their own organs or agreeing to the recovery of organs from

relatives. Participants who had not signed organ donation cards had higher CMI mistrust scores. The researchers' Organ Donation Questionnaire featured "Yes" or "No" questions to measure mistrust specific to the allocation process that included: "Are wealthy people and celebrities moved to the top of the list faster than 'regular people'?" and "There are probably many instances in which a person has been heavily drugged, then awakens to find he or she has had an organ removed for a black market transplant" (Terrell et al., 2004, p. 59).

Siminoff et al. (2003) interviewed 61 African American families in Pennsylvania and Ohio and concluded that Black families who were less trusting of the healthcare system were more likely to believe that individuals who had fame or fortune would have a greater likelihood of being organ recipients. According to some researchers, White people are twice as likely to donate as African Americans due in large part to mistrust of the organ donation system (Reinhart & Lilly, 2020; Salim et al., 2010).

The mistrust of Whites extends to healthcare professionals, according to Baughn et al. (2010). African Americans perceive a less positive experience when interacting with physicians and do not believe that they will receive the same quality of care as Whites. Physicians receive a higher patient satisfaction rating when they are of the same ethnic background as patients. This tendency to mistrust White healthcare professionals could influence African Americans' willingness to donate organs or consent to permitting the organs of relatives to be recovered (Salim, 2010).

Black U.S. students (n=182) from two Seventh-Day Adventist colleges identified Black Americans as more likely than White students to perceive racism in the healthcare system. Consequently, this was associated with a significant reduction in willingness to donate organs. Lack of trust came from the perception that physicians would forego lifesaving measures if they

viewed the patient as a potential donor (Cort & Cort, 2008; Morgan et al., 2008; Siminoff, 2006). In another study, an African American female respondent said, “God forbid something happened to him, you know, they gonna be thirsty to take his organs. They gonna be extra thirsty. Not even trying to see if the family okay. They gonna be, ‘Well, he signed this paper’” (Quick et al., 2012, p. 726).

### **Allocation**

The literature demonstrates that African Americans are not convinced that the allocation process is objective. Respondents reported the belief that race and class play a role in the allocation of resources particularly when it comes to organ donation (Jacob Arriola et al., 2005). In one study, African American high school students expressed an awareness of the longer wait times for those in their community as compared to non-African Americans (Spigner et al., 2003). Additionally, Blacks in the UK expressed concern regarding the possibility that donor organs could be “used without consent for other purposes like medical research” (Morgan, 2006). Participants in one study pointed to professional basketball player, Alonzo Mourning, and his experience on the waiting list. In their opinion, his wait time for a kidney was short because he had money and was a famous athlete (Quick et al., 2012). In a qualitative study involving African American clergy (n=26) and the organ and tissue donation decision-making process, one participant expressed that the concern of Blacks is that their donated organs would go to “. . . those people with money, or who know someone, or White people . . . providing for other groups rather than people in the community” (Jacob Arriola et al., 2007).

### **Religion**

Another contributing factor to African Americans’ lack of willingness to donate organs is the concern that donation may be in conflict with their Judeo-Christian beliefs (Callender et al.,

1991; Callender & Miles, 2010; Morgan & Cannon, 2003). Since religion is not an easy construct to measure, the literature is mixed regarding this factor and organ donation. Some researchers rate the frequency of church attendance as a measure of religiosity. Rumsey et al. (2003) developed the Organ Donation Attitude Survey (ODAS) to assess attitudes regarding organ donation. They asked 190 undergraduate students (6-7% Black or Hispanic) at a Midwestern university to rate themselves on a scale of 1 to 10 with “1” being “Not Religious” and “10” being “Very Religious.” The more religious students considered themselves to be, the less accepting they were of organ donation. Additionally, based on a cross-sectional telephone survey which asked similar questions about religion and organ donation, Boulware et al. (2002) also concluded that religious beliefs are important barriers to organ donation in African Americans.

Robinson et al. (2014) sought to understand religious beliefs as they relate to organ donation, with different findings in a mostly African American sample. The researchers measured religious service attendance (“How often do you attend religious services during the average month?”), religiosity (“How religious would you say you are?”), spirituality (“How spiritual would you say you are?”), religious norms (“I’ve been taught that organ donation is against my religion.”), and donation intention. Of 436 survey participants who self-identified as Black/African American among a total of 492 people, there was no consistent relationship among religious service attendance and donor intention. Surprisingly, subjective religiosity was not a factor when signing a donor card; spirituality was not associated with willingness to donate. The researchers conceded that more work is needed to explore the relationship of spirituality and organ donation intention. With regard to religious norms, the findings suggest that respondents who had been taught that donation was against their religion were less willing to serve as donors.

According to the study, African Americans' faith often guides their decision-making, but the religion's position on organ donation is seldom discussed or scarcely known. Researchers also speculated that when in doubt, individuals default to their own personal beliefs regarding donation.

In a study of 144 African American adults in California, a statistically significant number agreed with the statement, "My church would approve of me donating my organs" (Law & McNiesh, 2012). Similarly, Brown (2012) surveyed 55 African American sorority and church members using a 10-question online survey. Using a 5-point Likert scale, participants indicated their agreement or disagreement. Fifty-two percent strongly disagreed and 32% disagreed with the statement, "I feel there are religious /spiritual reasons not to be an organ donor."

Because church is an integral part of the African American community, researchers recruited participants from predominantly Black congregations to both investigate donor intention as well as develop interventions to increase organ donation. Jacob Arriola et al. (2005) examined the experiences and values that contribute to supportive attitudes related to organ and tissue donation by administering a questionnaire and conducting focus groups with African American clergy (n=26) and parishioners (n=42) from 7 churches in Atlanta, Georgia. In the clergy focus groups, respondents were asked about the church's views on organ and tissue donation and transplantation. They reported that while the church does not have an official stance on donation, clergy have not done an adequate job of addressing this issue with parishioners. Two years later, Jacob Arriola et al. (2007) explored the role of clergy in organ and tissue donation education among African American congregants by conducting focus groups with clergy from seven churches of different Protestant Christian denominations.

The findings indicated that although African American clergy do not object to organ donation, they have concern about perceived inequalities in the allocation process. Secondly, it was found that parishioners find religious concerns to be a major barrier to organ donation even though the issue is not problematic for the clergy. The researchers argue that Black churches have great influence on the African American community and religious beliefs shape the attitudes among African Americans. The researchers state that uninformed parishioners look to the religious leaders for their faith's take on organ donation. When clergy are silent, the default position is against donation (Jacob Arriola et al., 2007). Andrews et al. designed a study to test the effectiveness of using lay health advisors to increase organ donation of parishioners. Participants from 22 Black churches in Southeast Michigan (n=1254) were part of a randomized and controlled trial to increase donor designation. The results revealed that pastoral support is vital to the success of any intervention designed to increase donation intention. The presence of lay health leaders was found to have a positive effect on donor registration.

### **Bodily Integrity**

Several studies cited the desire to maintain bodily integrity as a contributor to African Americans' reduced willingness to consent to organ donation (Morgan & Cannon, 2003). Urban high school students in a total of three Washington campuses (n=247) were surveyed to determine their knowledge and opinions about organ donation. While 46% of the students identified as African American, 76% of the African American students reported not being likely to want to be organ donors. All students who did not select "I want to be an organ donor" were given the opportunity to give a rationale for their decision. The most commonly selected reason (29%) was that the body should remain intact after death. Of the 29% of students who felt that the body should remain whole, 60% were African American (Spigner et al., 2002). Terrell et al.



(2004) administered the Organ Donation Questionnaire in which participants were asked to answer “yes” or “no” to questions which included, “Donation of organs disfigures that person’s body?” Researchers concluded that Black females are less willing than Black males to allow organs to be harvested from family members because of concerns about disfigurement of the deceased. Respondents in a study examining attitudes related to donation expressed concern about the need to maintain the integrity of the body for heaven and listed mutilation as a barrier (Jacob Arriola et al., 2005). Quick et al. (2012) conducted focus groups in which African American respondents also reported bodily mutilation as adversely affecting their willingness to donate; mostly, they felt it would render the body unfit for an open casket funeral. For instance, one respondent expressed a popular sentiment in ethnic communities: “My own cousin told me . . . she wanted to die . . . with everything she had . . . and be buried just like she came” (p. 926).

In a study of organ donation in three ethnic populations (Malay, Chinese, and Indian) in Southeast Asia, the fear of disfigurement was a limiting factor across all ethnic groups (Wong, 2010). Black Londoners of Caribbean descent (n=14)—who had been interviewed to understand their attitudes and perceptions surrounding kidney donor registration—found the possibility of disfigurement unsettling (Morgan et al., 2008). The results of a knowledge questionnaire revealed that 58% of respondents who had not signed a donor card rated the following statement as correct: “It is not possible to have an open-casket funeral service following organ donation” (Morgan & Cannon, 2003).

### **Misperceptions**

Quick et al. (2012) sought insight into the perceptions of organ donation among African American, Hispanic, and White high school students by conducting focus groups. Some students reported not perceiving themselves as having “good enough” organs for donation. One

respondent said, “. . . All the things [drugs] I did . . . my organs are no good, so I might as well leave them there and let them rot”(p. 926). Some students perceived death and cadaveric organ donation as too morbid to discuss or think about. Other teens viewed the topic of organ donation as unimportant and not pertinent. Some respondents were concerned that the organs would go to waste if a suitable match could not be found. Waste in the literal sense could occur if the organs were unable to save a life or if the recipient’s quality of life did not improve. Waste in the figurative sense could occur if the recipient’s moral character was in question or if the potential recipient was not a good steward of their original organ (s) and health. Recipient death was also a concern: “. . . I heard that . . . they have to take just massive quantities of medication . . . for the body to accept the donor . . . and then after a few years of that organ, don’t they have to get a new one, in some situations?” (p. 927).

### **Donor Intention**

The aim of several studies was to increase donor intention (Flemming, et al, 2020). Terrell et al. (2004) reported that altruism was a significant predictor of one’s willingness to become a designated donor. For African American respondents, donor intention was a significant indicator of an individual’s willingness to donate their own organs, but not the organs of loved ones and family members. The researchers also asked participants if they had ever signed a driver’s license card or any other document consenting to having their organs transplanted. Andrews et al. (2012) designed a study to increase donor designation based on statistics indicating that 61% of Whites stated that they had signed a donor card versus 31% of Blacks. The researchers’ use of lay advisors in Black churches (n=211) resulted in an increase in minority enrollment in organ donor registries.

In a factor analysis study involving the Organ Donation Attitude Survey (Rumsey et al., 2003), participants were asked to indicate their level of agreement or disagreement with the statements, "I have signed an organ donor card or the back of my driver's license" and "I am willing to have my organs donated after my death." For the last factor, Potential Organ Donors indicated an interest in being organ donors. Morgan and Cannon (2003) reported 40% of their sample had signed an organ donor card. Of the 14 people interviewed by researchers in the UK, all agreed with the idea of donation, but only 2 actually carried signed donor cards. The remaining 12 respondents had not given the matter any thought or were ambivalent and found the topic of organ donation difficult (Morgan et al., 2008).

### **Race and Class**

According to Vranic et al. (2014), African Americans' donor transplant rates are lower nationally compared to Whites. Also, African Americans and other minorities experience longer wait times for transplants (Kernodle, et al, 2021). Geographic location has the greatest impact on racial disparities in waiting times for kidney transplants.

To determine whether referral of potential organ donors was affected by race of the patient, Hartwig et al. (1993) conducted a retrospective chart audit in a regional trauma center serving a population that was 50% African American. African American donors were identified by staff as potential donors more than 2.4 times less often than Whites. Additionally, there were significantly fewer requests made of African American accident victims. A descriptive study involving procurement coordinators and patients who portrayed family members was conducted in Virginia to understand the roles of gender and ethnicity in procurement coordinator-family interactions surrounding the organ donation discussion. One scenario involved an African American family and the other involved a White family. African American procurement

coordinators expressed more positive affect when interacting with the African American family versus the White family. White procurement coordinators had less positive affect in the scenario involving African American family as measured by the Positive Affect Scale of the Siminoff Communication Content and Affect Program (a coding system). Researchers concluded that race plays a significant role in the identification of potential organ donors (Baughn et al., 2010; Vranic et al., 2014).

Studies involving retrospective chart reviews examined the phenomenon from the perspective of class. When researchers reviewed the charts of Alabama decedents (n=1292), they discovered that household income was not statistically different between African Americans who consented to donation and African Americans who did not consent (DuBay et al., 2012).

### **Family Discussion**

Family members who are unaware of the donor's wishes are often conflicted about making a decision regarding organ donation (Dodd-McCue & Tartaglia, 2007). Spigner et al. (2002) reported that 29% of African American 18-year-olds versus 38% of their non-African American counterparts knew what their family thought about organ donation; 29% versus 32% had ever discussed organ donation with their family. Morgan and Cannon (2003) included a question about whether the respondent had discussed their decision of whether or not to be an organ donor with their family. Of the 60% (n=186) of the participants who had not signed a donor card, approximately 55% had not spoken to family regarding organ donation wishes. When comparing the perceptions of Black and White families regarding organ donation, researchers discovered that 32.7% of African American families had discussed the wishes of the patient as opposed to 49.7% of Whites (Siminoff et al., 2003). Dodd-McCue and Tartaglia (2007) published a study which determined that among African Americans surveyed, 100% of

those who did not consent to organ donation did not know the wishes of their deceased family member.

### **Discussion**

These studies indicate that African Americans' experiences with organ donation are varied and the population is not homogeneous. However, the barriers of mistrust, concerns for body integrity, and religious concerns were common threads among African Americans reported in the literature. Additionally, the disparate number of African Americans consenting to organ and tissue donation compared with Whites is a common theme in the literature. The age of the respondents in this review ranged from high school students to adults over the age of 50 years. Researchers who studied high schoolers concluded that health education on the topic of organ donation needs to be youth-oriented as well as culturally sensitive.

The findings of these studies are the result of exploring the phenomenon from different perspectives. The researchers who focused on the attitudes related to organ donation found that attitudes toward donation are shaped by whether an individual has ever known a transplant recipient, as those individuals are more inclined to consent to donation. Clergy who clearly inform parishioners about the fact that most of the major religions do not prohibit organ donation are able to shift the attitudes toward acceptance. When parishioners are unaware of their religion's stance regarding donation, the default attitude tends to be refusal to donate. Positive attitudes toward donation are more likely when there have been discussions among family members about their wishes in the event of brain death, according to the data. In many of the studies related to attitude, knowledge played an important role in dispelling myths that adversely affect willingness to donate. The prominent myths include (a) fear of premature death if an individual is a designated donor (e.g., withholding life-saving treatment in order to harvest

organs); (b) inability to have an open-casket funeral due to mutilation; and (c) the prohibition of donation based on religion.

The goal for some studies was to assess and evaluate interventions designed to increase donor intention. The aim for most of these studies was to increase donor registration among African Americans. Peer or lay teaching was found to be an effective intervention. In interventional studies involving churches, researchers found that pastoral support was vital to the success of any intervention.

The current body of literature is primarily focused on the well-documented barriers to donation and efforts to increase organ donation intention in African Americans and other communities of color. The specific gaps in the literature include: (a) factors that go into the decision-making process for African Americans; (b) perceptions of African Americans throughout the process of the cadaveric donation request; (c) impact of the patient's narrative on the family's decision; (d) how the potential donor presents at the time of the request; and (e) outcomes of a culturally sensitive approach by clinicians.

### **Limitations**

This review focuses heavily on the barriers to organ donation. However, the literature also mentions motivating factors such as altruism with regard to organ donation. Some study participants desired to turn their loss of an organ into an opportunity to help someone in need. Some participants' altruism extended beyond the African American community as they were willing to donate an organ to improve the quality of life for any individual in need, regardless of the individual's ethnicity (Jacob Arriola et al., 2005; Jacob Arriola et al., 2007; Morgan et al., 2008).

Because of the diversity within the African American community, some findings are not generalizable. Not all African Americans identify with the major Protestant religions, so those individuals would not be represented in the literature involving churches and clergy. Also, it would be difficult to draw conclusions based on socio-economic status and willingness to donate because the samples might not capture participants from all socio-economic statuses.

### **Strengths**

The robustness of some of the studies was enhanced by the large sample size (Andrews et al., 2012; Boulware et al., 2002; DuBay et al., 2012; Eckhoff et al., 2007; Resnicow et al., 2010; Robinson et al., 2014). Among the studies with the aim of increasing donation intention, the findings confirmed the importance of family discussion prior to the death of a loved one (Morgan & Cannon, 2003). A significant finding among the studies about the role of religion with African Americans and organ donation was that the involvement of religious leaders can have a positive effect and dispel negative beliefs and attitudes (Rumsey et al., 2003). Researchers who utilized the qualitative method of focus groups were able to yield greater understanding of ways to increase organ donation intention (Quick et al., 2012).

### **Recommendations**

Previous studies on organ donation have used mostly quantitative or mixed methods for data collection. Some of the studies compared and contrasted African Americans, other ethnic minorities, and Whites. This dissertation was designed to address the substantive and methodological issues identified in this review of the literature. In order to advance the study of organ donation, this dissertation was designed to address three major gaps in the literature. First, the interpretive research approach helped to illuminate the complexities of African Americans' decision process as it relates to organ donation. An interpretive lens allowed the researcher to fill

in the gaps in understanding left by quantitative methods (van Manen, 1990). An interpretive phenomenological approach allowed researchers to gain understanding of the lived experiences of family members and how those experiences influenced a family's decision to donate or not. IP seeks to understand how the families responded based on what matters and their understandings about the world. An IP guided study has allowed the researcher to study the families' experiences through analysis of narratives generated by interviews (Benner et al., 2009).

Second, participants were selected solely on the basis of having been approached to consent without regard for SES, or religious affiliation. When included in this study, these three elements provided rich insight into the phenomenon that has not been observed thus far. Results inform researchers in the area of creating a social media campaign designed to educate and promote organ donation in the African American community. Future research related to deceased organ donation consent will add to the body of knowledge by studying the cultural sensitivity and awareness of procurement coordinators and those who approach family and loved ones of the potential donor.

### **Concluding Discussion**

The disparity in organ donation and transplantation rates in African Americans is of great concern for a population which suffers disproportionately from chronic conditions which lead to organ failure. The concern has led to various studies on the topic of organ donation and African Americans. An overall summary of the findings of this review reveals barriers and facilitators to organ donation in African Americans. This review also demonstrates the need for further research that addresses gaps in knowledge and lead to improved donations rates and successful transplant rates for African Americans.



By studying the actual experiences and narratives of African Americans who have been asked to consent to the harvesting of organs from their loved ones—both those who agreed to do so and those who did not—we gained insight into the understandings and interactions that factor into those decisions in moments of great existential difficulty. Viewing this phenomenon through an interpretive lens helps answer questions such as: In what ways was the experience of being asked to consent to organ donation consistent or inconsistent with previous expectations and healthcare experiences? Does the question of consent for organ donation raise race-specific concerns about fair treatment that have not been articulated? How do family members integrate their narratives about the experience of deciding whether to donate the organs of their loved ones within the larger narratives of their relationships with them? How have the experiences of friends and acquaintances shaped their decision to consent?

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## Chapter II: Methods

### Study Aim

This study sought to understand the experiences of African Americans with organ donation requests and how their experience may impact their decision to consent.

- **Specific Aim #1:** Using in-depth qualitative interviews, explore and describe the experiences of African American family members who have been asked to donate the organs of a deceased loved one.

### Study Design and Analytic Approach

A descriptive, exploratory study design, using interpretive phenomenology as the analytic approach was utilized. van Manen (1990) describes the interpretive process as one which seeks to gain a deeper understanding of the nature of our everyday experiences. Phenomenologists study persons, events and practices in their own terms in order to understand the lived understanding of the participants, their activities and what they see as valuable and important to themselves and others (Benner, 1994). Interpretive phenomenology assumes that there is no “view from nowhere” when studying human beings. Heidegger’s term, “forestructure” refers to a three-fold structure of interpretation based on understanding: first, fore-having, which is what we bring from our background into the situation and our interpretation, or a taken-for-granted background (Dreyfus, 1991). Secondly, fore-sight is the point of view from which the interpretation is made (Benner, 1994). Lastly, fore-conception refers to the idea that the investigator has expectations of what may be uncovered in an interpretation (Dreyfus, 1991). This study was shaped by my prior experience and observations as a kidney/pancreas transplant coordinator. In the tradition of Heidegger (1962), my a priori understanding is presumed through the hermeneutic process, but the researcher works to understand what is taken for granted by



studying specific instances where participants experience a breakdown in the usual routines, practices, and activities. The instance of organ donation request, almost by definition, represents such a breakdown for most people, and is shaped for African Americans by a long history of exploitation and mistrust (Morgan & Cannon, 2003). My relating to being a member of the African American community and a registered nurse transplant coordinator frame my understanding of this phenomenon.

### **Participants and Sampling**

This study utilized purposive sampling methods. This strategy is most appropriate because respondents are selected based on inclusion criteria that have relevance to the research inquiry (Tongco, 2007). The criteria for inclusion were: (a) English speaking, (b) identify as Black/African American adults 18 years or older, (c) U.S. residents, and (d) have been approached by healthcare professionals to donate the organs of a deceased family member. There were no restrictions on the time since the loved one passed. Although this may be a source of recall issues, this allows for variation that could potentially be analytically significant. Exclusion criteria included family members who were not the designated decision makers.

### **Recruitment**

Initially, the researcher planned to recruit utilizing the Donor Network West's Aftercare list as discussed in the research proposal. Donor Network West is an organ procurement and tissue recovery organization. This list is used to follow up on family members who were approached and asked to donate a loved one's organs, regardless of their final decision and is categorized by demographic information which includes ethnicity. Unfortunately, the Donor Network West's list was inaccessible due to limited staffing during COVID-19. Instead, participants (n=16) were recruited through social media posts and email lists through

professional and fraternal African American organizations, such as the National Black Nurses Association, National Society of Black Social Workers, Black Doctoral Network, Black Greek fraternal organizations (Kappa Alpha Psi, Inc., Alpha Phi Alpha, Inc) and Black Greek sororities (Alpha Kappa Alpha, Delta Sigma Theta). The small sample size is typical of studies using interpretive phenomenology, as the purpose of the study is not to achieve statistical generalizability, but to achieve a deeper understanding of participant experience. See Appendix 2 for descriptive information about study participants.

### **Eligibility and Consent Procedures**

A brief telephone screening was conducted with interested individuals to determine eligibility. Once eligibility was established, the investigator and participant proceeded to the consent process. Participants were consented using an IRB-approved consent form (see Appendix 3). Verbal consent was also obtained a second time before the interview commenced and the respondent was verbally notified that they could refuse or end the interview at any time. Additionally, the participants completed an IRB-approved demographic questionnaire (see Appendix 4)

### **Data Collection**

A semi-structured interview guide was developed by the researcher in collaboration with her dissertation committee. Open-ended questions were designed to elicit narratives about participants' experiences at the time of the organ donation request. The interviews were semi-structured to allow the interviewer to listen carefully for the participant's own narratives and follow-up with probes to clarify or fill in any missing pieces of the story. The guide was piloted and elicited rich narrative data (see Interview Guide, Appendix 1).

Interviews (n=20 interviews with 16 individuals) lasted approximately 45 to 60 minutes and were conducted via a mutually agreed upon method (telephone, in person, or via Zoom). After COVID-19 pandemic precautions were in force, all interviews were conducted using Zoom. Four individuals participated in a second interview. Repeat interviews allow the researcher to confirm that they have understood the participant's responses and ask follow-up clarifying questions. In the hermeneutic tradition, interviews that are more interactive, focusing on the stories of their experiences yield more valuable data than highly structured interviews which may not encourage participants to elaborate (Cohen et al., 2000, p. 61).

Each participant received a \$10 gift card for the first interview and those participating in a second interview received an additional \$15 gift card at the conclusion of their respective interviews. Interviews were audio-recorded, transcribed by the researcher or an approved professional transcription service, and reviewed against tapes for accuracy.

### **Data Management and Participant Privacy Protections**

The interviews were transcribed verbatim, and data were anonymized for transcription purposes. Audiotapes and transcripts were stored in a locked, secure place and the original audio of the interview is to be destroyed at the end of the study. Multiple precautions were taken to maintain privacy in the research setting. Identifying information was stored separately from interview transcripts. In addition, interview transcripts were kept in a locked file cabinet separate from participants' contact information and electronic data was stored on an encrypted computer or disk. Only the PI and Co-PI had access to consent forms.

### **Sample**

A total of 16 individuals were interviewed between January 1, 2018 and November 30, 2021 (see Appendix 2 for details on participants).

## Data Analysis

Interview data were coded using qualitative data analysis software (Atlas.ti 8) which aids in data management, sorting, coding, and text interpretation. The analysis included reading whole interview transcripts, reviewing for accuracy, creating broad themes, then identifying segments of text that clustered around inductively developed categories, identifying direct quotes that captured what appeared to be the most important or salient themes or topic areas in the data, as well as codes to capture specific areas of interest identified through the literature review (see Appendix 5). For example, the code, *Organ donation as an African American* focused on the segments of the request process specific to the African American identity or racialized experiences.

Another code, Regrets/Changes- captured regrets about how the experience unfolded and /or advice to other African American families experiencing organ donation requests (see Appendix 6). The researcher also had a code for whole narratives or stories, which often provide clues to understanding their lived experience through how they position themselves and others within the story. Stories of breakdown often reveal more of the taken-for-granted worlds of participants.

Additionally, I kept both theoretical and interpretive notes, particularly noting any reference to the three main phenomenological constructs of embodiment, ways of being in the world, and concerns. The analysis involved memo writing to capture developing thoughts, concepts, theories and interpretations from early data collection through interpretive analysis (Charmaz, 2014). In phenomenological research, memo writing allows the researcher to enter the hermeneutic process of going back and forth between the data and interpretation, between parts and whole, and to capture gaps and contraindications in the data for further analysis. Narratives

are the result of collaboration between participant and interviewer. They help to disclose practices such as decision-making and invoke the arranging of facts and events in chronological order that forms a story which helps the reader gain understanding (Chan et al., 2010). The way in which the participant makes sense of the experience can provide rich analytic clues.

Using phenomenological methods, three narrative strategies were employed to interpret the data. Paradigm cases are whole cases (interviews) that are strong examples of a specific pattern of meaning. Thematic analysis requires the interviewer to read each case several times with the aim of arriving at a comprehensive analysis. Exemplars are stories that capture a particularly meaningful situation in a way that the meaning can be identified in another situation (Benner, 1994; Smith et al., 2009). These strategies are designed to provide the basis for entering practical worlds and understanding socially embedded knowledge (Benner, 1994). Two paradigm cases were developed into chapters based on the data analyzed for this study. One paradigm case calls attention to the imperative for clinicians to take the time to hear the narrative of the potential donor before asking a family member about donation. The other case reveals the difficulty of trying to anticipate such an unimaginable moment in advance.

### **Rigor**

To enhance rigor, whole interviews and sections of coded data were read and discussed with an interpretive research group of doctoral students and with the researcher's academic advisor and committee members. Emerging interpretations were examined alongside the text of interviews to ensure that analyses did not go beyond the data. Chapters were reviewed iteratively by the researcher and committee members.

Tracy has designed a conceptualization which allows researchers of different qualitative areas to evaluate excellence in qualitative research (Tracy, 2010). The criteria are (a) worthy

topic, (b) rich rigor, (c) sincerity, (d) credibility, (e) resonance, (f) significant contribution, (g) ethics, and (h) meaningful coherence. The issue of organ donation in the African American community is both relevant and timely, making it a worthy topic. There are disproportionate numbers of African Americans in need of donated cadaveric organs (UNOS, 2014). The criterion for rich rigor is met based on the sufficient sample size of 20 to 35 cases. Repeat interviews helped satisfy this criterion for this study. The goal of sincerity is achieved through self-reflexivity. As a former transplant coordinator, the researcher is transparent about the biases brought to the research in the selection of interview questions. As a novice researcher there was a learning curve with regard to interviewing techniques and skills such as avoiding the temptation to interrupt the narrator in order to ask every question listed on the interview guide. Additionally, the researcher's transparency regarding the challenges of recruitment. In order to address credibility, quoted sections of text allow readers to evaluate the researcher's interpretations. Tracy (2010), defines resonance as "the research's ability to meaningfully reverberate and affect an audience."

One narrator gave a heartfelt account of her inability to consent to the organ donation of her husband because, even though they had previously discussed organ donation, "he still had a heart beat . . . his heart was still beating!" The existential crisis faced by the narrator resonated because a beating heart is universally viewed as an indicator of life. Significant contribution is evident when someone has been liberated or empowered as a result of the research. These participants may be able to tell their stories about a very difficult time as well as offer advice to others ("If you had to give advice to another person or family about considering organ donation what would you tell them" and "Is there anything that would have made the experience of being approached . . . better . . . for you?"). When participants are able to have a voice, they often feel

empowered. Because of unethical research practices in the past, it is imperative that researchers adhere to procedural ethics. Part of CHR approval includes obtaining informed consent and protecting the privacy of participants. The study's participants were also informed that their participation was entirely voluntary. Meaningful coherence is demonstrated when the research achieves what it set out to accomplish.

### **Study Limitations**

Reflexivity is an important part of establishing methodological rigor (Tracy, 2010) The proposed study has several limitations. Participant recall bias could arguably be an issue since some participants were retelling events that occurred many years prior. As time passes, some of the details of a situation can become less vivid, but the point of a phenomenological study is not to identify “the facts” of a situation, but to capture the meaning of part of human experience. Experiential meanings for participants sometimes become clearer over time through the telling and retelling of the story.

The population being studied is a heterogeneous group having a wide range of experiences. The sample sizes in phenomenology are typically small; this prevents the researcher from being able to claim representativeness.

Use of telephone or computer-aided interviews creates some limitations. Potentially, there can be nuances that cannot be conveyed when interviewing a participant over the telephone. It is also challenging for the interviewer to demonstrate active listening with non-verbal cues during a phone interview. Video chatting is better but can be adversely affected by poor internet connection or technical distractions.

Some respondents who were recruited through advertisements on Craigslist.org were possibly motivated by the financial benefit (e.g., gift card[s]). Their recollection of events was

uncharacteristically vague in contrast to others who were recruited using snowball sampling, potentially limiting the usefulness of the interview data.

### **Dissemination**

In addition to seeking to disseminate the findings through peer reviewed journal publications , and professional conference presentations, I hope to use the findings to develop webinars/video-conferences for transplant coordinators and donor networks. Community forums and panels (to which participants in the study might be invited) are additional modes of dissemination.



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### Chapter III: David & Abigail Paradigm Case: Incongruence with Pre-Understanding

Abigail, a former homemaker now in her seventies, recalled being asked many years ago to donate the organs of her beloved husband David, who died unexpectedly. Her memory of that experience was still remarkably detailed.

David was an adored husband who cherished Abigail and their family. He was also very active and involved in their community. She attributed their civic engagement largely due to their upbringing in the South amid still-ongoing struggles for civil rights for African Americans.

Remembering David, Abigail said:

Ahh, that was my best friend. That was my husband which I loved dearly, and um, we were lovers. Considerate of one another. Had a lot of things in common.

The way we thought about things . . . um, and the things that we did. We were very, very much family oriented . . . he was . . . very community-minded, because of the struggle we had gone through.

Abigail was at home with David, a firefighter, when he collapsed and lost consciousness. She initiated CPR until the paramedics arrived. Abigail joined her husband and the paramedics in the ambulance as they traveled to the hospital.

When Abigail arrived at the hospital, she was hopeful that there would be a positive outcome. She recounted:

When we got there, you know . . . I was very, you know, positive that everything was going to be okay . . . Here I was expecting that I could hold on to . . . because all I could think about and believed was that my husband was going to make it.

The neurologist who evaluated David came to update Abigail. During the discussion, Abigail recalled being deeply hurt and angered by his lack of compassion, his insensitivity and perceived negativity as he abruptly informed her that David was brain-dead.

But um, they had to call in a specialist, and he said something I didn't like . . . he came in with the negatives. And I wanted to slap him [laughter]. But um, I thought he was very cold considering the situation . . . doctor had said to me that if he had known that my

husband had been resuscitated twice before he got to the hospital, he wouldn't have even come. And he asked me what I was even doing there anyway. What did I think, you know. He [David] was gone and what was, what was I complaining, what was I upset about . . . He's brain dead!

The neurologist's lack of empathy left such an impression that decades later, Abigail said she had never forgotten his name.

I could've hurt him really bad. When he came in with that attitude, you know, as if my husband was nothing! And why was I wasting his time.

Brain death was a foreign concept to Abigail. She struggled to process what the neurologist was saying about her beloved husband. She asked questions to seek understanding of what she was hearing. Her questions were met with a very cold and harsh response.

For the specialist interested primarily in brains, according to Abigail's narrative of what transpired, her husband was indeed "nothing"—only a nonfunctioning organ and thus apparently a waste of his time. For Abigail, the expectation was that a true physician would try to do "something" to save the person in his care, a person she still experienced in the moment as her beloved husband. She continued:

I'm like, "What?" He said, "It's just a waste of time!" And I'm like, I . . . I . . . said, "Well, can't you do something?" He said, "What are you going to do? He's dead!" . . . And the man kept saying, the man said, "Well, there is no brain functioning."

Abigail's interactions with two other physicians were in stark contrast to the neurologist.

Abigail described the emergency room doctor as having approached her in a much more caring, compassionate and supportive way. She felt that this doctor acknowledged David's humanity. Abigail sensed his concern and sincerity. The sense that "something was being done" at least was reassuring, allowing her the space to process what was taking place.

He was so much more considerate. He couldn't really tell me anything, but he made me feel at ease. That he was doing everything he could . . . He talked to me like I was a human being. And he talked TO me . . . Not AT me! He talked TO me. And he was considerate to the degree wherein he says, "Listen, I understand, right now this is . . .

[crying] hard for you, but we are going to do everything we can to help him. And I will keep you abreast of every-thing that is going on.” And so, I thanked him for it, you know. And I felt like he meant what he said, because he spoke to me honestly from his heart, you know.

The third doctor who interacted with Abigail was her family doctor, whom she had known for several years. This particular doctor was the one who approached her about organ donation. He was someone who Abigail trusted and gave her the sense that she was heard.

In particular, the third doctor explained the process and the time-sensitive nature of the request.

My GP, the family GP. He says, “You know, we are not getting any signals from [David]. The specialist says that he’s brain-dead . . . . This is difficult for me to do because I’ve known you guys for a long time, but knowing you guys, I must ask it anyway . . . I want to talk to you about donating[his] organs.”

Abigail was still trying to wrap her mind around being in the emergency room at all as a result of David collapsing such a short time ago at home. As the general practitioner continued to speak, Abigail began to question why the conversation was going in the direction of organ donation.

I was still reeling from the fact that we were in this hospital and all the stuff we were already going through. And then I said, “Well have you given up on him?” He says, “It is not that I have given up on him, but . . .”

The doctor continued to explain the donation process and the specific organs that could be donated. He acknowledged how difficult the conversation was for Abigail.

Abigail recalled the words of the general practitioner:

We have a time factor for harvesting. Excuse me for saying that, but that’s how we address it. We do have a time factor. Wherein the organs will be viable. After that, they won’t be any good. I wanna know how you feel about it and how would you feel about letting us have the organs. There’s[sic] some specific ones we’d like.”

As Abigail tried to comprehend the doctor’s request, she experienced a range of emotions. She was confused because she was being asked to donate, but she was still hopeful that David would recover. She was concerned that consenting to donation would signal to the healthcare providers

that he no longer needed care. Abigail was fearful to convey that message, wanting to believe that he could still recover.

Most importantly, Abigail needed to have the matter of there being no hope of him recovering settled before there could be any decision to consent to donate her husband's organs.

I was hearing him and not hearing him, because all I could think about and believed was that my husband was going to make it. And that it wouldn't be necessary. And also, I thought, I have to admit that I also thought if I say yes to you, you're not going to see what you can do to save my husband's life because you're going to take his organs . . . and if he wakes up—I don't know if he will wake up after you've taken them [chuckle] but I don't want to take a chance on you taking his organs before I know specifically, or within my heart I can agree there's no hope.

David and Abigail had discussed the idea of organ donation in the past. She was aware that he desired to be an organ donor and had made his wishes known by registering with the Department of Motor Vehicles.

However, Abigail's perception of death when they had talked about it previously was not at all consistent with David's current state.

Well at some point[he] and I had talked about things in general, and too because . . . he had seen people in life-or-death situations . . . I remember him telling me when he was getting ready to renew his license that he was going to be an organ donor . . . I wasn't concerned . . . I didn't say, "Oh, no." I said "Well okay, if that's what you" . . . at that point I didn't have any problem with it. I just figured that okay, if it came to that then, it would happen and be what it was going to be.

When she had discussed the plan earlier with her husband, she envisioned the circumstances in which the decision would occur would be very clear-cut and not ambiguous: "In my mind, he would be actually dead." Her interpretation of "actually dead," Abigail indicated, involved the absence of any respirations or a pulse.

But when the situation unfolded, Abigail was convinced that her husband was still alive because of the presence of a pulse. Her understanding of what constituted life involved the interconnectedness of the mind, body (heart, organs) and spirit. When she felt her husband's



heart still beating, there was a connection. In the Bible, matrimony is described as the two becoming one. As husband and wife David and Abigail's hearts were connected metaphorically. Touching his heart was not only a physical act; it was also emotional.

His heart was still beating. He didn't have to have, um any equipment for his heart to beat. His heart was still beating . . . his heart was beating. I felt it, hands on and touching, you know.

But I'm like, "His heart's beating! How can that be? They're all connected."

Abigail's decision-making process was complex. Her faith played a role in this process as she was seeking direction and guidance about trusting and believing that David would recover.

Furthermore, the unwavering belief that life would return to normal would be necessary to keep doubt at bay. This was important to Abigail because from her perspective, the presence of doubt, suggesting she had lost faith, might adversely affect David's survival:

I am a faith person. I'm a Christian and I believe in God and I know the miracles God can make and do. Even though God can resurrect the dead, I just felt like there's life there . . . I was not sure that was the decision to make because I had not been in prayer about it. I had been praying for him to be revived and healed, but I hadn't gone past that point of thinking that that was not going to happen. So, then I didn't want to let any doubt creep in either.

When she shared her concerns about wanting to wait for guidance from God before deciding, her family physician graciously allowed her time to make her decision.

I told him about my concerns and about being a Christian and believing God . . . He gave me the time frame and he says, "What I'll do is, I'll give you a little while to think about [it]. Now, I don't want to pressure you and I'm not trying to pressure you, but I'll come back in . . . hours and then hopefully, you've had the time to think about it and we'll see if the miracle has happened." And so I was okay.

The time gave Abigail the opportunity to ". . . get back to what [she] needed to do in order to believe that [David] . . . was going to be okay." When the physician returned after a period of time, Abigail still did not have an answer because her hope that David would be okay was buoyed by the fact that his heart was still beating.

Ultimately, Abigail could not reconcile the fact that David's heart was still beating with the idea of saying yes to donation. To say yes would have meant murdering her dear husband and killing forever the hope that they could again be together. She could not reconcile the continued heartbeat with her husband being dead.

I couldn't give my permission because I was holding on to him being okay . . . I couldn't make that decision because his heart was beating . . . And so, I couldn't say yes to the doctor because of [his beating heart] . . . Now, like I said, if he had been in an accident or something where they had called me and said he was gone, I would have immediately said yes. But it was this fact that the heart was still beating and I felt like I would have been killing him. I would have been killing him if I had said "yes." But there are some people who could get past that, but I couldn't.

Abigail took personal responsibility for the choice she made. She did not consult anyone as part of her decision-making process. She fiercely guarded her role as life-long partner and advocate:

No, I didn't open that up for anybody. I didn't want anybody else's opinion. He was my husband, he wasn't yours.

She denied having any concerns regarding funeral arrangements when making her decision about organ donation because she avoided "going there" in reference to her acceptance of David's death.

When asked if anything would have made the experience of being asked to donate her husband's organs better, Abigail recounted her challenge with what she defined as an indicator of life: a heartbeat. It was her belief that consenting to organ donation would be synonymous with ending David's life.

Yes! I could have easily made that decision because I would have felt like, okay, he's gone, you know. But the fact that his heart was still beating. I felt, if I said yes, I was taking his life! Couldn't do that to my husband. I mean that's the way I felt about it. You're asking me to cut off life from him . . . and make that MY decision . . . I couldn't do it.

## Conclusion

David and Abigail's paradigm case offers insight into how the decision about donation is shaped by implicit expectations at the time of being approached. If the family's idea of what death looks like is not consistent with how their loved one is presenting, the decision can be very difficult and nuanced. Even under circumstances where family members have previously discussed organ donation, the way they imagine the situation unfolding may be radically different than the reality of the medical diagnosis of brain death. If the loved one has made their wishes known in advance it is likely that the discussion did not include considering fully the possibilities for what the situation might look like.

This case demonstrates the need for education of families and significant others and potential decision-makers in the area of possible end-of-life scenarios. Individuals are educated about the process of identifying themselves as an organ donor on their driver's license; however, potential donor families are unaware of the details of what the organ donation circumstances may actually be. In the abstract, they agree on a plan, but the actual, world-disrupting, unexpected and time-pressured circumstances, which may include the presence of a heartbeat, are not at all what they imagined. A variety of tools, such as written materials describing possible scenarios, or videos to discuss with family members considering their organ donation wishes, could prove to be very effective in reducing the discontinuity between expectations and reality in a traumatic situation.

This case reveals the difficulty of trying to anticipate such an unimaginable moment in life. This difficulty is only compounded by the time-sensitive nature of organ donation requests. There is pressure to make an irrevocable decision that can potentially affect the lives of several

individuals. In some instances, the decision is made by default when the window of opportunity is closed due to time constraints, as the next chapter discusses.

## Chapter IV: African Americans & Organ Donation Requests Chapter

Hundreds of years of systemic and institutional racism in the United States have adversely affected African Americans (Adler & Stewart, 2010). Social determinants of health such as education, environment, employment have contributed significantly to poorer health outcomes for this group. Research also demonstrates that the higher rates of illness and death and shortened life expectancy of African Americans are the result of health disparities (Centers for Disease Control and Prevention [CDC], 2021). African Americans have also been disproportionately affected by chronic illnesses such as diabetes, heart disease and kidney disease (CDC, 2021). As a result, this population suffers organ failure requiring organ transplantation at a disparate rate. In the past, researchers have focused on the barriers to both living and cadaveric organ donation in the African American community (Andrews et al., 2012; Dodd-McCue & Tartaglia, 2007; Goldberg et al., 2013; Morgan et al., 2008). What has not been studied extensively is how organ donation requests are experienced among African American family members. A greater understanding of these lived experiences, and how they might inform changes in donation request practices, could potentially have a positive effect on donation rates. This chapter draws on in-depth narrative interview data from family members asked to donate the organs of a loved one to analyze the ways in which identity as an African American shaped/informed the experience

### **Seeing Representation**

When interacting with health care providers, African Americans as well as other ethnic communities appreciate having a provider and staff who speak their language, look like them and/or demonstrate an understanding of their culture and influences. Seeing representation in the hospital setting can have a positive effect on family members. Bethany, a daughter and sister in

her fifties, shared her observations regarding her mother's caregivers and how impactful it was to see how the staff members of color interacted with her mother, as contrasted with the other caregivers on the unit:

But the presence of seeing staff that looked like us, was so amazing and so calming, that we were shocked at first because we hadn't been in the hospitals in years. So we didn't even know that there was a large population of black people that were running the front desk . . . And then when they would come in to like, turn her, they would, they would call her what we called her. So, we're like "Mama turn, Mama turn." So, they'd be like, "Hey, Mama, you ready for your lunch? Hey, Mama." Right? But honestly, we didn't, we only got that interaction from the nurses of color. We did not get that interaction from the other nurses that were white. And that was huge for us three little black girls wanting to make sure that our Mama was fine . . . even when the house cleaning would come in to clean . . . and we did notice a difference between the races and how we were treated.

Staff of color were attentive to and comfortable taking their cues from the family and using the same language as the daughters in speaking to their mother, which the family experienced as reassuring. The daughters rotated being at their mother's bedside for the purpose of providing advocacy and safety for their beloved mother because they had no expectation that their African American loved one would necessarily receive the best care as a person of color in a hospital with majority white caregivers and staff.

### **Provider Assumptions**

In the absence of representation, there is sometimes the perception that the providers lack cultural understanding and sensitivity when addressing African American patients and family members. There are times when explicit assumptions have been made by providers as to the relative knowledge, status and power African American families possess. Abigail, whose husband David was declared brain-dead, was approached to donate his organs. She was a nurturer who advocated for her loved ones in every aspect of life. She regularly sought out health-related information available to lay persons. Abigail declined the organ donation request for several reasons, but among them referenced her prior personal interactions with physicians.

Well you know, with my own personal experience with different doctors who are not African American, we don't get talked TO. We don't get, uh . . . I get talked AT. And then I get insulted. And then I get ignored. You can see the . . . you can see the uh, uh that shade coming down over their face when you're sitting there telling them about . . . the problems or the symptoms. And then when somebody just out-and-out insults you and asks you, "What college did you go to? What doctor's degree did you have?" They say you're supposed to be an advocate for yourself. But if you're gonna get your stupid ego, uh, bruised because I asked you a question, then you can't help me. I can't trust you either.

In describing this particular interaction from an earlier time, Abigail suggests that it also related to how she experienced the request for organ donation later. In her narrative, she was seeking information from a non-African American doctor about her own health concerns.

Rather than being recognized as someone with knowledge and a perspective of her own, she was disparaged, and felt it was related to her racial identity. This was experienced as dismissiveness, as the doctor regarded her as not being worthy of being heard or her perspective acknowledged. The questions reportedly asked about Abigail's medical training and her educational background were legitimately perceived as being insulting and confrontational—an assertion of power—rather than as empathetic. Perhaps this doctor felt intimidated by Abigail's questioning, but the result was increased mistrust that was carried forward in time to impact her later experience when her husband died.

### **Misinterpretation**

An example of misinterpretation occurred when, according to his sister Naomi, James was informed by his doctors that he was in organ failure and there was nothing more that could be done, medically. According to Naomi, describing the interaction, James accepted the prognosis.

And James looked at the doctor and he told the doctor, he said, "Well, I guess I'll just get ready to go on home." And the doctor said, "No, you don't understand." James says, "Man, get out of here. You don't know who Jesus is." And he was an Asian doctor. He looked at him, tailed and turned to, went on out the door.

James's reference to "going home," as his Naomi knew, was about leaving this temporary life and going to his ultimate home with Jesus: heaven. The physician's lack of understanding caused him to interpret James' statement literally, as in being discharged from the hospital to his residence. Naomi's mention of the doctor's ethnicity is important because it suggests that he was seen as an outsider who displayed no understanding of or interest in his patient's world. The doctor, rather than recognizing that James was speaking figuratively in relation to his spiritual belief, took his words literally, missing an opportunity to compassionately ask more about what James meant—and to better understand his attitude about facing death.

### **Racialized Communication**

Non-African American providers' communication style may be perceived as patronizing or condescending, adversely affecting the relationship with the potential donor family. When family members experience this, they are not at all motivated to be open to the donation request. Naomi, who decided not to donate her brother, James' organs described her frustration with the physician's communication, which she perceived as insulting to her intelligence.

The doctor kept going over the same thing, just over the same thing. Like we didn't understand what he was saying. And I became very irritated and I told him, I said, "We have good comprehension. Our level of intelligence comprehended exactly what you said the first time you said it. Five times repeating it, it's doing no good for any of us."

But I just know that for me as an African-American female, how I am approached is so vitally important to my reaction.

Naomi's world is shaped through the lens of being an African-American woman. She lives life in a society that does not appreciate or esteem her ethnicity nor her gender. This sense of devaluation directly affects the way she interacts with those who treat her with disrespect.

Naomi's interaction was another instance of an individual feeling talked AT. At this point in the conversation there was a breakdown which could have been mitigated by the provider asking



questions to sensitively explore Naomi's understanding and perception of what was being said. Also, the physician could have rephrased his comments rather than repeating the same phrase. Since there was no evidence of Naomi having any auditory deficits, repeating the same thing over and over was perceived by Naomi as an insult to her intelligence.

### **Trust**

Trust is of major importance in any patient-provider relationship. In the absence of trust, there is no willingness to work together toward a common goal. African American families will not be open to the idea of organ donation if they feel there is a lack of trustworthiness of the requestor. When asked if African American families would feel a lack of trust, Abigail said:

Yes, definitely, a lack of trust . . . I don't believe you have my best interest at heart . . . I can't trust you either. They are very hesitant . . . If we felt that way [trusting], it wouldn't be any problem with donating, you know, organs at all. We don't have that reassurance, though.

Sincerity is a component of trust. This characteristic, although not easily defined is about how the healthcare provider is perceived.

Yes . . . I'll pick up on whether you are sincere or not. But you got to be sincere. Really sincere. And I believe African American families will readily, you know . . . because we'll pick up on it. We will, because we've been in this way [racism] so long, so many years. You don't have to tell me anything. I'll know. I will know instinctively. And I won't judge you prior to, but I will know whether you are telling the truth. Whether you mean what you say. (Abigail)

African Americans who do not trust the requestor will also not trust the process of cadaveric organ donation.

Several participants questioned whether the allocation process would be fair to potential African American recipients of their loved one's organs:

There are exceptions to every rule, but as a whole, we are very distrusting . . . . At the medical system—is how a lot of African Americans just don't trust doctors. Because of . . . the prejudice and the racism . . . . All that plays into [consent to donate] . . . (Seth)

So, hopefully they're not trying to exterminate the Black folks by, you know, their organs. You see those movies where, and I'm not saying this is happening but I'm pretty sure it has happened, especially in foreign countries or if you go—or I don't know. People are selling organs, as well. So, I think that has, to an extent, an impact on a decision . . . . You know, trying to get our organs, for us to donate our organs . . . for us because let's face facts and deal with reality. I mean, we've gone through a lot and we still are. (Leah)

Medical mistrust in the African American community stems from historical abuses, unethical research, and mistreatment on the part of the medical community such as the Tuskegee syphilis study and the acquisition of tissue samples from Henrietta Lacks, an African American woman, without the permission or knowledge of Mrs. Lacks or her family (Vernon, 2020). Also, as a result of racism, African American patients have suffered disproportionately from chronic illness and have higher morbidity and mortality rates than whites. The past medical injustices cause African Americans to feel that there is a disregard for Black bodies and even a commoditization of their organs and tissue.

Even some participants who denied that being black affected their decision-making at times used descriptors suggesting they experienced the donation request through the prism of racism.

A family member approached for donation recalled that she had been asked about “harvesting” her loved one’s organs. Discussing her negative reaction, she evoked the “plantation” metaphor, linking the request with America’s long history of slavery and racism:

He were no garden, he were not on no plantation. What’s you harvesting? (Naomi)

But I had read about how Black people are treated and how, yes, we are leery about giving permission for, as an organ donor because we didn’t feel like the medical field, the medical practitioners, and the people would consider us to be as important as white people, so they would harvest our bodies quickly. (Abigail)

Abigail is referencing the historical exploitation of African Americans and their fears of a premature death in order for physicians to obtain their organs for donation (Afifi, 2006). Since

the Middle Passage, Black bodies were bought and sold as property. At one point in America's history they were reduced to being identified as three-fifths of a human (Asante, 1991). The overt devaluation of Black lives resulted in the perception that their organs and tissues could be easily used to be of value to others and a sense of anxiety about being treated as "less than" solely based on race.

Because of the violation and all taking place—the prejudice and the racism—it's still pretty much really really alive in this country as far as some people think that it's not, but it really is. (Seth)

We were about to lose our loved one, and you're worrying about taking his body apart, just picking and choosing what you want, and that's what I felt at first. (Naomi)

Here Naomi echoes the sentiment that Black bodies are expendable and the only value ascribed to them is based on what they can do for others.

Lydia, who declined to donate her son's organs, spoke about how mistrust contributed to her refusal to give consent. She was not convinced that the physician who was so excited about the quality of Maurice's organs and the potential benefits to recipients, genuinely had her family's best interest at heart. Lydia was angry with the provider because she believed that he might not try to save her beloved Maurice's life because he was anxious to harvest organs to transplant into someone else. However, she also feared some type of retribution if she did not consent to donate his organs.

The way he was talking and made me feel like he just he's you know he's given up on Maurice and the way that my son he was looking, he wasn't swollen or nothing like that. And he just was looking like he was sleep[ing]. So, in my mind, you know, I'm thinking, Oh, he can be okay. You have to understand I was mad at that doctor . . . . And that's why I was so against it [donation]. I always thought that I'd say he killed Maurice because I wouldn't donate his organs.

## Respect

African Americans feel dismissed, ignored and overlooked by a society that does not demonstrate value for them as human beings, as evidenced by the Black Lives Matter movement. Whether or not the family members felt respect for themselves or their loved one impacted their willingness to donate. Rebecca chose to donate her son Caleb's organs, in part because she felt empowered and respected by the requestor.

Because she showed such respect by acknowledging my pain first and giving her condolences and giving me the respect to ask permission of am I ready to discuss it? I felt she acknowledged my pain . . . . And I felt like she asked permission to discuss it. So, I felt like she gave the power to decide. She didn't take power from anybody. (Rebecca)

## Loved One's Story

One of the ways that healthcare providers can counter the belief that African Americans' loved ones' organs are merely commodities is to display empathy and appreciate the significance of the request in terms of the importance of their loved one's story.

I think for African American families, they would have to have some kind of assurance . . . . They would have to pick up something, feel something, see something from that person who is presenting this to them before they could with good conscience say "yes." We have to also know, or feel that that person truly understood that this is, my precious, precious family member . . . . And I need you to understand how important that person is to me . . . . And the fact that this person is important to me, you know (Abigail).

Abigail expressed the importance of acknowledging the loved one's personhood.

Family members want clinicians to be mindful of the fact that their loved one was a valued part of their family and world long before they became a patient. Their value did not cease upon admission to the hospital.

Bethany, who donated her mother's eyes, said:

I would want to tell them the story of the wonderful human being that possess those eyes, and maybe tell them all the things that she had seen in her life growing up in Mississippi during civil rights, right? Her work history having to pick cotton, having to be a maid. All of that going to segregated schools? I would be like, "Okay, let me tell you about your

[her] eyes.” Yes. Yeah, I did. But I, but even though I wasn’t afforded that opportunity, it still didn’t stop me from wanting to give the gift to someone else that might have needed them. (Bethany)

Bethany’s narrative about her mother exemplifies the importance of taking the time to hear the story of the loved one. This is not simply a matter of agreeing to donate a part of a body, a thing. Rather, the decision about her mother’s body involves recognizing the deep wisdom and experience accumulated across a lifetime of work, living in circumstances shaped by being African American in the south during a time of limited work opportunities and amidst a struggle for civil rights. In evoking the many things seen by these eyes, Bethany conveyed that the gift of her mother’s eyes means more than the physical organs: It means the gift is an extension of the meaningful and historically significant life that was seen through those eyes.

### **Lack of Knowledge**

Respondents cited a lack of knowledge around the organ donation process as a unique issue in the community. As people of color, they had concerns about the role of race in organ and tissue matching.

I got to thinking, eyes are eyes, whether you’re black, white, doesn’t matter. So, it doesn’t make a difference if . . . from a white person to put into a black person, you know what I’m saying? Does the body work like that? Like a puzzle? You can just take one piece from one place and put it in another place or it’s more than that, complicated in transplantation? I guess the eyes, it must be pretty universal. I’m not sure. Another thing, I don’t know what kind of person they were putting [them in]. They might have had a black person that received them. I really don’t know. Once you donate, you don’t really know. (Mary)

Mary was examining the role of race in organ donation-specifically the eyes. She recognized that in many areas of her world, the social construct of race mattered. However, she questioned the significance of race when tissues such as the corneas are transplanted.

When asked if the decision to donate is different for African American families, Mary responded:

Don't take this the wrong way, and you can put a label on whatever. I wonder because we're not educated, and I don't mean college educated, because we're not given enough information and because people like me, if I have an attitude, "Well, why should I donate my father's eyes?"

Mary's response indicated that it was her impression that African Americans might be more inclined to consent to donation if there was more information from the medical community about cadaveric donation, specifically targeted to members of the African American community. She posited that more information could allow her community to understand the life-saving benefits of donating and its relevance.

The medical term, "brain death" is known and understood by many lay people who do not have clinical training. For African American family members who lack knowledge of this term's meaning, it can be difficult to understand what a declaration of brain death means for their loved one especially when being approached about deceased organ donation. Lydia expressed a lack of understanding when the doctor asked about donating her son's organs:

And I said no, because he was gone. Because he's got, they didn't they didn't tell me what brain dead, meant. They didn't, you know, like you said his brain. They didn't but because of how he was looking. He, you know, he didn't look like anything was wrong with him. Maybe they didn't even explain what brain dead meant.

When asked if she thinks the decision to donate or not is different for African American families, Eve discussed the intersectionality of race and knowledge in the African American community.

Yes, definitely, because of the fact that . . . . And I'm going to say this: We, as African Americans, are not as knowledgeable, not as compassionate. I don't want to say we're ignorant, but you have to look at the . . . . Let's see, how can we say it?

You hear about donor lists. You hear about organ transplant. You hear it's mostly Caucasians. I don't want anybody to have my organs. I want to take mine with me. This is because we don't understand. We don't understand that life goes on, and you have something that can save somebody else. I don't want to sound like I'm crazy, but you can bless somebody else with what you have, because you can't use it anymore . . . . I guess it's hard to say, but we're not told . . . . Black people are not taught. . . . I just think the Afro American race should be more educated about it. I guess that's my feeling. This should be something that we're more educated about. When you go to the driver's license and

you check off, you should have a pamphlet, so you could take that pamphlet home and read. (Eve)

While there were some gaps in Bethany's knowledge regarding the process of matching in organ donation, she was clear about the time-sensitive nature of procurement and transplantation and about how race impacted her decision. She wanted to ensure that her mother's corneas could be transplanted into someone who had a need. As an African American she was aware of the disparities in health care outcomes for African Americans, therefore she did not want to risk having an African American not getting a needed organ because of a lack of a suitable donor.

And I did think I'm like, Can I [request an African American recipient] when I called them back? I go, 'cause I'm making the distinction to make sure it goes to an African American. And they're like, "No," I was like, I can't or like, No, I was like, okay, just wanted to ask, because that would be extra nice for us . . . . But I think because I had thought I had an understanding that sometimes in African American community, right, our DNA is different. Our general makeup is different. And it might be harder for someone who was African American to get an organ that matches them. And I wanted to be part of the solution to give them an opportunity first, because of what I perceived to be that you know, it just would be harder because of just like if you get a kidney transplant, right. Something has to match within you for that to take. And I kind of attach that on to her eyes. And that's why it was important to me because I wanted, I didn't want someone who was African American who needed them, and then couldn't get them because they weren't available based on the match not being appropriate. So that I might have a match, can we make it happen? And that that was my reasoning behind that . . . . Um, honestly, everything that I drew upon, about organ donation came from whatever movies I watched, or whatever . . . . Yeah, I know. It's Hollywood. And I know there's, there's always some truth to everything that's in Hollywood . . . . So, I knew I could not wait on anyone else to make this decision. Or else they would lose the opportunity to transplant them. So, I did have knowledge of that. And I'm pretty sure I gained that knowledge from Hollywood cinema, television documentaries, that I've watched. (Bethany)

### **Lack of Prior Organ Donation Discussion**

Respondents stated that organ donation requests are especially challenging because organ donation is not regularly discussed within African American families and communities. And because there is no discussion, intentions are not known. When the loved one has made their

intentions known, verbally or in writing, it makes it easier for the family to respond to requests in a timely manner and feel assured that they are honoring their loved one's wishes.



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## Chapter V: Congruence with Loved One's Narrative Paradigm Case

### Mary

Mary, a 53-year-old mother, daughter, and sister, works as a substitute teacher in the Southern region of the United States. Mary was approached to donate the organs of her father, John, and later her sister, Martha. For Mary, the experience of being asked to donate her father's organs seemed to shape how she responded when, much later, she was asked to donate her sister's organs after her sister's murder at the hands of her partner.

Mary described her father as a television technician by trade who regularly installed rooftop antennae long before the advent of cable television. According to Mary, John was quite intelligent and could have been an entrepreneur running his own business rather than working for someone else as he seems to have done for much of his life. John was well-known in the community for his ability to repair things, but had disappointed Mary with his unrealized potential. John was “. . . always a follower and never a leader . . . one of his lackluster things he would do is barter.” For Mary and her siblings, his bartering for things in exchange for work meant that the family chronically suffered want: “. . . we need[ed] food more than we need[ed] ten alarm clocks.” Mary suggested that she and her siblings went hungry and although her father was well-liked in the community, she clearly still felt he had failed to provide adequately for his family. Mary intimated that John valued possessions (or perhaps the process of bargaining for them) over people:

So, I don't know if he had some OCD hoarder issues or whatever the deal was, but I found more things than I did food in my refrigerator, so it was pretty tough growing up. Never had the things that we needed.

Throughout her narratives, Mary drew attention to her father's perceived flaws. She resented that he was overgenerous with others but seemingly failed to see how he was letting down his own children:

He was a popular guy since he was always fixing things for [other] people.

Later in life, after the children were adults, John had lived on his own in Louisiana until he lost his home to hurricane Katrina. This huge loss was the beginning of a downward spiral in his life. He stayed with his adult children until he was able to secure a FEMA-issued trailer. However, he eventually lost the FEMA trailer due to the presence of formaldehyde, and for some period he moved from place to place. Eventually, he lost his only companion, his dog, and most of his possessions. At the time of his death, Mary described him as a very old man who had suffered compounded losses including most importantly, his dignity.

When Mary was asked to tell the story of what happened when she learned that John had passed, she felt it important to give this background and history. She wanted to acknowledge his personhood prior to discussing his passing. She described who John was in the world, seemingly understanding that John was shaped by his world:

You know, I can bring you back a little bit before that [his death], because it kinda tells the story. He was a Hurricane Katrina survivor, if that's the right word, and it was just too much for him.

So, he had to deal with that issue [loss of the trailer], with the grieving issues that came from that. He lost [hope], depression. So, he just kinda lost his dignity. Not being able to take care of himself, lost his home, lost his trailer, lost his pet.

Mary mentioned twice that John ended up with no home and virtually no belongings, after apparently being someone whose life had been characterized by accumulating many things.

And he would always say, "This is not my home, this is not my home. All my belongings are in those three bags." The three brown paper bags got down to one brown paper bag. And all I remember [is] "this is not my home; my home is in that brown paper bag."

At the time of John's passing, Mary had not been in recent contact with him due to his lack of a fixed abode, so it was surprising to be notified by the hospital.

So, it was like when we found out, I didn't even know, you know . . . . So, we found out he had passed away and you know.

Mary questioned how John could have value as a potential organ donor due to his advanced age and illness(es). When Mary and her siblings were approached to donate John's organs, she was surprised that someone over the age of 70 would have any viable organs for donation.

He was an old man when he passed away and his mind was getting old. He was just old physically, mentally. What do you do [with] a guy that's old? They said because of the age we can donate the eyes. Never thought about organ donation and I know my dad was [old]. I thought organ donation was for the young people.

When asked if Mary conferred with any family members to make the decision about donating her father's organs, Mary reported that her siblings opted out of the decision-making process, leaving the responsibility of deciding about donation with her.

Well, they said, "Oh, you make the decision." And I'm like, "No, this is a family decision."

She was taken aback to realize that John, who had failed to provide enough for the family in her childhood and then sustained so much loss himself in later life, had anything to give in death.

When Mary asked the doctor for more specifics, she was informed that her father's eyes could be donated. John's eyes were an important part of her narrative:

It felt strange. So, they said, "Well, we can always donate the eyes. His eyes still were able to be donated."

John's eyes had ironic significance for Mary as her father had "always said he had eyes in the back of his head," and was always aware of what his children and others were up to.

In a way, I can see him just shaking his head and I'm like "the eyes? Why the eyes? I don't understand why the eyes."

Mary had a sense of the importance of John's eyes when she realized that the healthcare providers kept her father's organs functioning with supportive measures in the hopes that his family would consent to donation which could be life-changing for a recipient.

They saved my dad's eyes. They asked us about donating the eyes. They kept him alive to get the eyes.

Although Mary's narrative expressed her disappointment in her father, she also made comments suggesting a protectiveness toward him that indicated that she had, to some degree, a sense of loyalty and that they still had a relationship: "I didn't want nobody touching him. They saved MY\_dad's eyes." Initially she was against the idea of donation, confiding, "I was kind of freaked out." But according to Mary, the doctor informed her that there was a young girl in the same hospital who was "in need of a pair of eyes." Mary had many technical questions regarding transplanting an older adult's eyes into a child's body. Eventually, she realized that she was going to need to make a decision before the window of opportunity to donate was closed.

Mary described the experience of deciding to donate her father's eyes as "heartwarming but freaky at the same time." It was heartwarming because a child was going to get the gift of sight but "freaky" because they were taking a part of her father's body that was no longer useful to him, and putting it into a stranger's body. After weighing the benefit to the potential recipient, Mary decided to consent to the donation, regarding it as a way to memorialize him while also helping a little girl. The fact that the girl was in the same hospital "was the selling point," according to Mary. In addition to being able to help someone else, Mary was reassured when she learned that eye prostheses could be used for John's funeral service.

Mary had never been willing to donate her own organs and indicated that she did not like the idea before this experience. Initially, she thought it would be hypocritical to consider donating her loved one's organs when she wasn't willing to donate her own.

Who am I to do something with someone else's organs I wouldn't do with my own? It sounds sacrilegious.

Mary resolved this dilemma by focusing on the potential recipient. Asked if the potential recipient's ethnicity factored into her decision to consent, Mary indicated that she was able to confirm that the recipient was African American. (It is highly unusual for the donor family and the recipient to meet so close to the time of donation.) However, she felt she would have made the same decision regardless, as it was the fact that the recipient was a child that mattered most:

Yeah. She was African American, so I'm sure of that. But I think just the fact that it was a child, I don't think it [being African American] was an added issue. If it were a white or African American. The fact that it's a child, that just poked at my heart strings. It was the fact that it was a child I probably wouldn't have done it [consent] if it wouldn't have been for the little girl.

When asked what would have made the experience of being approached to donate her father's eyes better or more comfortable, Mary discussed the importance of educating the family and discussing organ donation prior to a loved one's passing. Mary was not mandating how every family should address the idea of organ donation, but she understood that it was important that the family's consent or refusal should be informed, should be respected no matter what choice was made, and should be in alignment with any memorial service and burial plans. While she suggested a brochure as a possible way to accomplish this, she also acknowledged the challenge of conveying all this in that way:

I think that if they would have had some kind of brochure, you know, just I wouldn't even know how you'd put that in a brochure. Something that they could hand you that you could read over. It might say, "Do your homework and depending on the type of funeral service you plan on having [make your decision]."

For Mary, the donation of her aged father's eyes to a child seemed linked to the deprivation she herself had felt as a young child. Left with no possessions, he now was able to provide the gift of sight to help another child, through her decision. This experience changed Mary's views on

donation, as she described her second experience with a donation request when her sister was murdered.

When asked to describe her late sister, Martha, Mary spoke very fondly of her sister and described their relationship as close-knit. She also detailed the huge vacuum left following Martha's murder:

My sister was the world to me. We were so much alike. They used to call us twins and we weren't even twins. Just everything we did, we used to dress alike . . . just [a] very close-knit family, her being the only sister that I had, there's a void now.

Mary also spoke about who Martha was to others who knew her. She characterized Martha as a giving individual:

Oh gosh, just very outgoing, lovable, would do anything for anybody.

Mary detailed Martha's rocky relationship with the husband who murdered her. Martha's family was aware of the chronic problem of violence directed toward Martha:

She was in a marriage of 28 years and it was not always a good one. There had been restraining orders throughout the years. She had even gotten to the point where she was filing for separation. Ultimately, it was going to be the best.

When Mary shared the story of what happened when she learned of Martha's death, the family was not surprised at the assault, given the history, but they expressed disbelief over the extreme violence of the perpetrator as well as Martha's defenselessness:

When I got the phone call that she was a victim of domestic violence, we knew there were some close calls. It was just to get that phone call. But when someone gets gunshot wounds where they meant to shoot them, because that's the type of person that you are, how can you defend yourself with someone who has a gun? The fact that she went out like she did and she didn't even have a fighting chance on her own.

Mary mentioned the phone call again when recounting the story about how she began to understand that her sister might not survive:

We got a phone call from the hospital saying, "Your sister is up here and we're doing what we can, but it's not looking good."

Following the phone call, there was a range of emotions for Mary.

She was hopeful that her sister would be able to recover. She was prayerful that the doctors would have encouraging news when she arrived at the hospital. Mary questioned whether the cause of death was relevant in light of the loss of her dearest sister? Was she going to spend energy focusing on the brutal murder of her sister and the toxic relationship that led to the horrific death? Or instead, was Mary going to seek to find meaning and purpose in this “senseless” situation? Mary also gave thought to the role fate played in her beloved Martha’s passing:

You wait and pray for some miracle. Something good comes out of something bad. You want that good to be, because it’s senseless. Any type of, honestly, I think it wouldn’t have mattered what the circumstance was. I guess if some other way it was her time to go, I probably wouldn’t have been good about it.

Yet again, Mary was approached to consent to organ donation. And again, she questioned what could possibly be salvaged.

Mary knew that her sister was the victim of multiple gunshot wounds and was trying to process Martha’s death while trying to comprehend the doctor’s request:

Then one of the doctors asked, “What about organ donation?” There was almost nothing they could do [to try to save Martha] and the next thing I know, they’re saying organ donation and we’re thinking, “Really?” That’s the last thing on our minds, because we knew she was shot up, I mean shot up and they didn’t get into particulars, but it seemed like the doctor tells you this and you’re thinking, “What could possibly still be worth saving?”

The chance to make good out of a terrible situation was what motivated Mary to say yes. In doing so, Mary salvaged from a terrible situation the meaningful memory of her sister’s life as a generous, caring person.

Mary reported that the physician seemed stunned when she quickly consented. She recalled:



I agreed and they were really shocked that we would agree to it. It was like, “Okay, you’re asking us and then we say yeah and then you’re liked shocked.” What’s the catch? Why were they almost in tears when we said yes?

When Mary inquired about what could be salvaged for donation, she was told, again, that the eyes could be donated even after such a horrific death. In requesting consent, hospital staff apparently tried to offer statistics about organ donation, but Mary dismissed them, readily agreeing to donate her sister’s eyes. The decision, for Mary, was not based on cognitive processing of “facts,” but on the emotional continuity with who her sister was that the donation represented. She viewed the donation as a continuation of Martha’s life: Martha was still giving, even in death:

They said her eyes. If we would be willing to donate her eyes. There wasn’t anything viable but the eyes. I’m like, “The eyes?” If any good came out of this, it’s like, “Okay.” They were even trying to give us statistics and stuff and I’m like, “I don’t want to hear about all that, just if you can use her eyes, great, take it.” Knowing that [a recipient] is able to see because of her, just makes her be around twice.

In her interview, Mary brought up the issue of ethnicity and organ donation. Mary admitted to not being very knowledgeable about organ donation prior to identifying her preferences for end-of-life care and after death.

Mary now realized that eyes could be donated irrespective of the donor and recipient’s ethnicity. She was unaware of the ethnicity of the recipient of Martha’s eyes and indicated that it was of no consequence to her:

I don’t really know a lot about organ donation, other than [what] I got when I got to prearrange for my funeral and that’s when I realized that among African-Americans, not a lot of [them] donate their organs.

I got to thinking, eyes are eyes, whether you’re black, white, doesn’t matter. So, it doesn’t make a difference if [eyes] from a white person are put into a black person. I don’t know what kind of person they were putting [the eyes] in. They might have had a black person that received them. I really don’t know. Once you donate, you don’t really know.

Martha's family denied having any concerns about any potential impact of organ donation on the funeral arrangements and the burial. Maintaining bodily integrity was also not a concern. It is unclear if the brutal nature of her death had any impact on their indifference to having her eyes donated:

Defile the body in some way, yeah, I was not concerned about that. We were like, "Okay, whenever the hospital releases the body." Everything had happened so suddenly, so part of this time to arrange her funeral was better for us, if that [makes] any sense? If you can use it, use it.

Mary stated that the decision to donate would have been made easier had Martha made her wishes known prior to her untimely death.

Additionally, Mary maintained that families should discuss their wishes with their loved ones in advance:

I just got my [driver's] license renewed and there's a place, if you want to be an organ donor or not. She had nothing next to it, so I really don't know what her final wishes were. If I would have known that she wanted to be an organ donor and there was a box checked off, that would have made it so easier. Open up to people about it and [talk] about it ahead of time. Let your wishes be known legally. Don't wait until the person's dead . . . . You don't know if you're going to end up like my sister.

Mary expressed the importance of not only making one's wishes known, but also making funeral and burial arrangements in advance.

I'm ready. I'm ready whenever it is. I was approached [about organ donation] when I was prearranging my funeral. Be proactive about it. I do have plans. I even have my own urn.

With John's passing we learn about the history of John as an individual, as a father and ultimately, as an organ donor. Mary described her father as an individual who was intelligent but lacked ambition. He was content to help others through his vocation.

Unfortunately, for Mary and her siblings his assistance to others did not translate into provision for John's household. Prior to John's passing, John had experienced great loss throughout the years as a hurricane Katrina survivor who was displaced from his home. As a

result, John suffered multiple losses both materially and relationally as he was estranged from his family at the time of his death. Even though John was not a man of means during his lifetime, and was advanced in years, he was able to give the priceless gift of sight to an organ recipient. By linking her own sense of childhood deprivation with the donation her father enabled in death, Mary seemed to have integrated the two into a narrative that later informed her decision in the case of her sister.

Martha's story was one of tragedy. She was violently murdered by her estranged husband. Mary knew that her beloved sister had been a victim of domestic violence for many years. Mary and her brother were saddened greatly at the news of her hospitalization; however, they were not surprised. Although Martha had suffered multiple injuries and ultimately lost her life, Mary viewed organ donation as an opportunity to find meaning in the senseless loss of Martha's life. Again, in telling the story Mary integrates her memory of her sister as a generous and giving person with the decision Mary made to allow the organ donation.

These narratives of donation experience illustrate the way in which the decision to donate is shaped not only by the circumstances of the "ask" situation or by previous discussions about organ donation with the loved one. It is also shaped by the way the donation decision may integrate with or provide coherence or closure to narratives about sometimes painful or ambivalent relationships with the loved one. This calls attention to the imperative for clinicians to take the time to hear that narrative before asking a family member about donation.

## Chapter VI: Conclusions

The experience of being asked to donate the organs of a deceased loved one may present unique challenges for African Americans. It is vital to understand that this community experiences the world through the lens of living a society characterized by systemic racism.

Three key conclusions emerge from the findings of this study:

1. Family members asked to donate the organs of their loved ones had expectations of what death might look like that were sometimes not congruent with the loved one's physical presentation when the donation request was made;
2. In addition to the challenges of navigating an unanticipated donation request made of anyone, being African American may mean additional challenges through mistrust and systemic racism that affect communication, assumptions, perceived treatment and perceptions in the situation; and
3. Family members' narratives about their loved ones set up possibilities for clinicians to better understand how donation may be congruent or incongruent with families' understandings about their loved one. Sharing the narratives also opens ways for families to work through and reconcile the donation request with their loved one's life and legacy in the pressured moment of this world-disrupting loss.

### **Incongruent Expectations**

The paradigm cases illustrate how the decision about donation is shaped by implicit expectations at the time of being approached. Death is a social and cultural construct and not just physiological. For some, a poor quality of life, due to numerous medical interventions such as mechanical ventilation or intractable pain is synonymous with how they imagine death may look. The absence of an awareness of one's surroundings, or loved ones' presence, being unable to

communicate, and the absence of brain stem function is inconsistent with the definition of life for some individuals. Culturally, some believe that a comatose state indicates that the person's spirit is no longer present, and the individual is no longer alive, because the spirit or consciousness is the essence of life. But for others, still having a heartbeat means life.

Many people never talk about it at all. But even if they have, if the family has envisioned death coming in a manner which is not aligned with how their loved one is presenting, the decision can be very complicated and uncertain. In some traditional wedding vows, couples pledge to support each other, "in sickness and in health . . . until parted by death . . .," having perhaps unrealistic or even romanticized visions of death and not giving thought to the specific circumstances that may occur during end-of-life or even the possibility that one spouse will be responsible for making the decisions for the other.

The overwhelming majority of respondents in this study were also unprepared for the sudden change in their loved one's status. Some loved ones had declining health and were inpatients leading up to the request. Other loved ones experienced an unexpected occurrence such as a brain aneurysm. Several of the families were notified by clinicians that their loved one was the victim of violence and in one case, a self-inflicted gunshot to the head. The nature of the violence only compounded the grief of the family and made more difficult the decision about whether to donate.

The declaration of brain death can be particularly difficult for the family to comprehend, even if family members have previously discussed organ donation. If the loved one has made their wishes known in advance it is highly unlikely that the discussion included the full range of possible scenarios. The paradigm case discussed in Chapter III illustrates how the lack of knowledge of the range of possible end-of-life situations complicates decision-making.

In the state of California, advance designation as an organ donor involves registering at the Department of Motor Vehicles when applying for or renewing a California driver's license. However, the only requirement is to check "Yes" when asked if the individual wants to be an organ, eye and tissue donor. There is no required review, discussion or education about what this may involve for family members if and when such circumstances arise.

In addition to the DMV, most advance directives contain a section about organ donation where the individual can express their wishes as to whether or not they want to donate their organs upon their death. It is important to note that fewer than 25% of African Americans have completed advance directives. Only one of the participants in this study mentioned having an advance directive/pre-paid funeral arrangement, which they prepared as a result of their experience with their loved one's passing. Potential donor families are usually unaware of the details of how the organ donation circumstances may present. In theory, they agree with organ donation but when the unimaginable occurs in real-time, the decision can be wrenching. If the loved one's vital signs continue to present with or without life-support and no brain activity, will the family be able to entertain the idea of organ donation under these circumstances?

Additionally, the decision can be more difficult to make due to the time-sensitive nature of the request. Clinicians understand that there is a short window of opportunity to retrieve organs in order improve the outcomes of the recipient(s). Once a family consents, the patient's treatment shifts and the clock begins ticking. The goal becomes well-perfused organs and tissues in preparation for retrieval and transplantation. There is lots of coordination between the transplant surgeons, contacting and preparing the potential recipient(s). If there are any delays that occur in this process, there is a possibility that the organs and tissues can lose their viability. The physician's expectations are now based on meeting the physiological needs of the potential

donor as their patient. These expectations are not shared by the family of the potential donor, who are experiencing a life-changing situation and trying to process the poor prognosis from the physician.

### **Systemic Racism and Health Care Providers**

To be African American means that there are distinctive concerns that show up. One's world and situation shape each other. African Americans' perceptions are shaped by living in a society characterized by racism and racist practices,, From within their perspective, they're in a world shaped by their experiences and history in this country. Systemic racism is a lived experience that shapes how the organ donation request situation is perceived.

The findings reveal that representation matters. One respondent reported that she felt a difference in the treatment her loved one received from caregivers and staff who looked like her and her family. She perceived that the staff members of color responded to her loved one's needs in a similar way to the family's response. These staff members demonstrated a sense of familiarity and community for the family by hearing the language family members used and comfortably referring to the patient as "Mama". Another respondent who had a negative experience with her loved one's care and the consent request, was deliberate in mentioning that the physician was from a different ethnic group, suggesting that there was little or no commonality in culture or values that could be drawn upon in the interaction.

For some participants, the way they were approached was seen as culturally insensitive. A participant not specifically discussed in earlier chapters felt the clinician was clueless in approaching her while she, as the designated decisionmaker, was surrounded by other family members. This designated decision maker for the family initially said no when approached, feeling compelled to respond in the negative because they were surrounded by family who were

opposed to organ donation. Later, the decision-maker spoke with the physician away from the family and gave consent. This individual explained that they initially did not feel free to give consent because the doctor violated the family's sense of order and decorum. Whenever people mention something, it is an indication that it matters in their world.

Clinicians from outside the community may enter the room unaware of the mistrust based in racist and historical personal experiences with racism and their possible affect on the response of the family when asked to donate. One wife explained that she could sense whether or not a provider was sincere in their interactions with patients and family. African Americans may be more inclined to consider what the provider is asking when they are able to discern genuineness.

Participants expressed their mistrust of the healthcare system based on feeling like “guinea pigs,” recalling unethical research practices in the United States that affected African Americans disproportionately. They also spoke of their reluctance to consent to organ donation for fear of their loved one's organs being sold. Many described African Americans as generally mistrusting of healthcare systems and more specifically questioned the equity of the allocation process. These concerns are rooted in actual historical exploitation of African American bodies in research and healthcare. It is crucial that the providers recognize that the reluctance of the family to consent may not be personal but a factor of different social worlds in which the physician and the family move. There was the fear by some that their loved one would be killed or allowed to die in retaliation for withholding consent to donate. For these reasons, some in the African American community have been opposed to being a designated organ donor.

Respondents also identified a non-therapeutic communication style used by physicians. For some, it was the doctor repeating the same message which was perceived by the family as an insult to their intelligence. One respondent described being “talked down to” in a manner that



was lacking in empathy and compassion for the family, such as when a neurologist explained to a wife that if he had been aware that her husband was resuscitated twice in the field, he would have never treated him because it would have been “a waste of time.” This same wife described being “talked at” instead of “talked to” when some providers communicated with her. When a sister heard the term “harvest” being used regarding the process of removing organs or tissues from her brother, it conjured thoughts of plantations where enslaved Africans were forced to pick cotton and other crops. She also felt that he was being viewed as a commodity..

In the African American community, the topic of cadaveric organ donation is commonly not discussed, leading to a lack of knowledge regarding the entire process. The vast majority of participants denied knowing anyone who had received or donated an organ prior to being approached. They also were unaware of the timeline for transplantation. Two respondents inquired about the allocation process, with one asking if her mother’s eyes could be designated for an African American recipient. Another family member denied having a preference for the recipient’s race/ethnicity, but instead was motivated to consent when informed that the possible recipient was a little girl. Several respondents agreed that death and dying are taboo subjects within the community. In some cultures, there is the idea that discussing death and dying will cause it to occur. As a result of nothing being put in writing regarding end-of-life, donation or funeral arrangements, African Americans are often unaware of their family member’s wishes.

Based on the narratives in this study, there is a clear power differential between the clinicians and the family, which may be exacerbated by the racialized experiences family members have. One spouse reported being asked by the physician about whether she had medical training. Her perception was that the clinician was denigrating her ability to understand of the process and minimizing the validity of her hopes for her husband’s recovery, exploiting the

power differential between them. Instead of considering organ donation, she wanted to first be certain that every measure was being taken to treat her husband, no matter how remote the possibility of his recovering from a vegetative state.

### **Congruence with Loved One's Narrative**

Congruence with loved ones' narrative represents the importance of the provider having some awareness of the patient's narrative, who the patient is and how they show up in the family's stories about them. As discussed above, African American families and non-African American providers often move in different social worlds, therefore it is imperative that the families are able to bring the providers into their loved one's world. As Chapter 5 illustrates, though one participant's father was not a man of means during his lifetime, and was advanced in years, he was able to give the priceless gift of sight to an organ recipient. By linking her own sense of childhood deprivation with the donation her father enabled in death, she was able to change her father's legacy to one of giving as opposed to one of lack. Her father's narrative later informed her decision in the case of her sister. Her sister's life was one of generosity and kindness that ended in a violent manner. Giving the gift of life made sense because it allowed something positive to come from a tragedy. A mother shared that her son had always said he wanted to be a fireman because they save lives. She viewed organ donation as a way to honor his wish to save lives.

Another respondent's primary care provider had cared for the entire family over the course of many years and was familiar with the loved one's narrative. Not surprisingly, the respondent reported having a more positive experience with being approached by this physician to donate. Families want the clinicians to understand and appreciate how important their loved one is to them, why they matter. As described in Chapter 4, a daughter who consented to

donating her mother's eyes wanted to communicate the story of her mother. She wanted to tell them about all that her mom's eyes had seen while growing up in the rural south.

## **Implications**

### **Implications for Practice**

Current health inequities, in addition to historic discrimination contribute to African Americans' feelings of mistrust and perceptions of disregard and disrespect. It is important that providers are taught the skills necessary to approach African Americans in a manner that conveys empathy and compassion and is mindful of the historical experiences and terminology that could be racially charged. These perceptions are the lens through which they view the world. Whenever an individual or group feels acknowledged and valued, they are more receptive to hearing and receiving information from others. Also, people feel seen when someone takes the time to get to know about them, their interests, dreams, and more. This calls attention to the imperative for clinicians to take the time to hear the narrative of the patient before asking a family member about donation. This period of time need not be long to be effective. A few minutes of seeking to understand the person's story ("Tell me about your loved one") can have a huge impact on achieving a positive outcome to the request by demonstrating an openness to hear whatever matters to the family member.

### **Research**

Further research is needed to examine the process of the organ donation request particularly as it relates to African Americans. Researchers could examine differences in the family dynamics that shape decision-making about organ donation. What are the roles of the individuals being approached? Who are the gatekeepers, the family spokespersons? How do families go about making decisions when there isn't a crisis and does this change when a crisis

occurs? What happens if the matriarch or patriarch becomes the patient? Is it more effective to approach the entire family as a group or speak to the designated decision-maker alone?

Research could also explore whether an educational intervention conducted in conjunction with advance directive discussions could better prepare families for the range of presentations they may encounter at end of life, as discussed below.

Often in healthcare, people of color value and appreciate being treated by a clinician who shares their cultural background and values. There is a need for representation to help people feel understood. Additional research could include interviewing participants about whether the ethnicity and/or race of the healthcare provider had any influence on their decision.

### **Education and Policy**

The findings of this study suggest that a variety of tools could be employed to better address the topic of organ donation preemptively. When the Department of Motor Vehicles asks motorists to indicate their organ donor status, it could potentially include an optional link to some key points about the donation process for consideration. Just as the DMV conducts online tests for driver knowledge, information about the organ donation process could be presented in a similar brief online educational module. While this could not cover all important information, reviewing it might promote engagement in more advance planning discussion with family members.

Clinicians engaged in obtaining advance directives could use educational interventions such as written materials describing some of the possible scenarios that could lead to family members being approached to donate. Another strategy could utilize video presentations to initiate discussion amongst family members considering their respective organ donation wishes.

These interventions could potentially be effective in reducing the discontinuity between expectations and reality in an end-of-life situation.

With regard to advance directives, low-cost interventions such as free online tools are needed to allow for greater access to advance care planning as the cost of meeting with an estate planning attorney can be prohibitive for some in communities of color. The interventions could also include education surrounding the importance of making one's wishes known in a legal document.

Educational interventions are not just limited to non-medical persons. Providers could benefit greatly from learning how to approach African American families with cultural sensitivity and in a manner which takes into account the historical mistreatment of African Americans in this country. Having an understanding that being "colorblind" means that if African Americans are not seen in their full authentic selves, then they are not seen. Many clinicians' education may not have prepared them to fully understand that color, race and ethnicity shape how people of color move about in this world in every aspect of their being. Education focused solely or even primarily on procedural diagnosis and treatment fails to acknowledge the day-to-day struggles of feeling or being prejudged and therefore constantly having to strive to be twice as good, twice as smart, being viewed as suspicious, overcoming the presumption of guilt, yet not too aggressive to overcome the stereotypes that are an integral part of a racialized society. These daily obstacles and the expertise to overcome or navigate through them in workplaces, schools, healthcare settings and society overall are not within the experience of those who are not people of color.

Clinician education could require evidence-based training that identifies the unique ways of interacting with and approaching African American families. This training would not be a

recipe or set of generalizations. Instead, the educational materials could include historical factors that affect African Americans socially and medically. In relation to organ donation in particular, such training could also include vignettes drawn on paradigm cases such as those reported in this dissertation, offering culturally sensitive techniques and behaviors that could serve as exemplars.

Taken together, the findings of this study help make visible how the experience of being asked to donate the organs of a loved one is shaped by prior understandings about death, the racialized situations of African Americans, and the openness to or lack of hearing the stories of family members even under conditions of time pressures. In order to explore solutions to any issue, it is important to have insight into the processes that influence individuals. This research serves as a great start to being able to address the disparity in organ donation rates within the African American community.

## Appendix 1: Interview Guide

Participant # \_\_\_\_\_

Hello. Thank you so much for taking the time to meet with me today. The reason I wanted to talk with you is because I am interested in your experiences with being asked to consent to organ donation of a loved one. Basically, what I would like is for you to tell me about how you came to the decision whether to consent or not. Before we get started, I just want to remind you that your participation in this interview is completely voluntary. You should feel free at any time to let me know if you need a break or if you don't want to talk about a certain topic. You can also let me know if you want to stop the interview at any time.

1. First, can you just tell me a little bit about yourself and your relationship to your loved one?
2. Tell me a bit about your loved one. What was he or she like?
3. Can you tell me a story about your loved one that captures who s/he really was?
4. Can you tell me the story of what happened when you learned that your loved one had died. Possible probes:
  - What led up to the death and how did it progress?
  - Were there recent events that preceded the death? Any other important history?
  - How was the news communicated to you and by whom?
  - What happened next?
5. Tell me what it was like being asked about donating [name's] organs.
6. How did you make the decision about donating [Name's] organs?
  - What did you do during the time you were making your decision?

- What were you thinking and feeling at that time?
  - - Who did you talk to or who helped you make the decision?
  - Were there dissenting opinions in your family or other people in your life?
7. Tell me about what you knew about organ donation before you were approached.
    - What had you heard about it or what experiences had you had with organ donation before this happened?
  8. What did you end up deciding about organ donation?
    - How did you come to that decision?
    - Were there family members or friends who helped you come to the decision?
  9. Tell me about your experiences with memorial or funeral arrangements if you had one.
  10. Were there any specific issues about the arrangements that you thought about in making your decision?
  11. Is there anything that would have made the experience of being approached to consider organ donation better or more comfortable for you?
  12. As you look back, with the benefit of time, is there anything you would consider doing differently?
  13. If you had to give advice to another person or family about considering organ donation what would you tell them?
  14. Do you think this decision is different for African American families?
    - What factors might make this decision unique for African American families?
    - What if any experiences of racism in health care, and other areas of life, might influence African Americans' decisions about organ donation?
  15. Is there anything else you would like to tell me about your experience today?



16. Is there anything I should have asked you about, but didn't?

Thank you so much for your time. I really appreciate your willingness to share this difficult experience with me.

Additional questions from Kit: It is not in your interview guide, but maybe it is in the demographic questions? What was the informant's relationship with the deceased? What was their recent history together? (Living together? Sharing time together?)

Are there any relationship factors that played a role in the decision to donate or not donate the loved one's organs?

Appendix 2: Descriptive Information About Study Participants

**Table 2.1**  
***Study Participants***

<u>Respondent Name</u>	<u>Age</u>	<u>Gender</u>	<u>Education</u>	<u>Income</u>	<u>Relationship to Deceased</u>	<u># of Interviews</u>
April	68	Female	High School	\$41K-\$50K	Wife & Aunt	2
Benjamin	Declined	Male	High School	Declined to state	Family Friend	1
Bernice	Declined	Female	High School	Declined to state	Granddaughter	1
Bethany	47	Female	Grad Degree	Declined to state	Daughter	2
Abigail	73	Female	High School	Declined to state	Wife	1
Esther	71	Female	Declined	Declined to state	Mother	1
Eve	64	Female	High School	\$51,000-\$70,000	Aunt	1
Hannah	28	Female	Some College	\$21,000-\$30,000	Daughter	1
Mary	53	Female	College Grad	\$31,000-\$40,000	Daughter & Sister	2
Leah	63	Female	High School	Declined to state	Niece	1
Lydia	Declined	Female	Declined	Declined to state	Mother	1
Naomi	64	Female	Trade School	Declined to state	Sister	2
Rachel	Declined	Female	Declined	Declined to state	Daughter	1
Rebecca	Declined	Female	Declined	Declined to state	Mother	1
Sarah	Declined	Female	Declined	Declined to state	Mother	1
Seth	54	Male	Some College	\$31,000-\$40,00	Son	1
N=16						N=20

## Appendix 3: IRB-Approved Consent Form

**Study Title:** Exploring the experiences of African Americans who have been asked to consider donating the organs of a deceased family member.

This is a research study about the experiences of African Americans who consent (or not) to donate the organs of a deceased family member. The study researcher Debra Law of the UCSF Department of Nursing and Social and Behavioral Sciences, will explain this study to you. Ms. Law is a registered nurse and graduate student at the School of Nursing. Her research is being supervised by Ruth Malone, PhD, RN. Dr. Malone is a Professor in the Department of Social and Behavioral Sciences.

Research studies include only people who choose to take part. Please take your time to make your decision about participating, and discuss your decision with your family or friends if you wish. If you have any questions, you may ask the researchers.

You are being asked to take part in this study because you self-identify as an African American adult and have been approached within the last year to donate the organs of a deceased family member

### **Why is this study being done?**

The purpose of this study is to learn more about how African American adults 'experiences when approached about donating the organs of a deceased person. I hope to learn more about what people think about and how they make their decisions about whether or not to agree to organ donation.

### **Who pays for this study?**

This study is not funded at this time.

### **How many people will take part in this study?**

About 20-35 people will take part in this study

### **What will happen if I take part in this research study?**

If you agree, the following procedures will occur:

- The researcher will interview you in a private office or location of your choice. The

researcher will ask you to describe your experiences with organ donation. The interview will take between 1 and 2 hours.

- The researcher will make a sound recording of your conversation. After the interview, someone will type into a computer a transcription of what's on the tape and will remove any mention of names. The sound recording will then be destroyed.
- The researcher will ask you if you are willing to be contacted for any questions about the conversation you had. The researcher might also ask you whether you are willing to participate in a follow-up interview. The decision whether or not to answer questions or have a second interview is completely up to you.

### **How long will I be in the study?**

The total time required for participation will be at most 4 hours. This includes 45-90 minutes to complete the initial interview. Additionally, there could be time spent within the total time period for 1-2 follow-up interviews if needed for clarification.

### **Can I stop being in the study?**

Yes. You can decide to stop at any time. Just tell the study researcher right away if you wish to stop being in the study.

Also, the study researcher may stop you from taking part in this study at any time if he or she believes it is in your best interest, or if the study is stopped.

### **What side effects or risks can I expect from being in the study?.**

- Some of the questions may make you uncomfortable or upset, but you are free to decline to answer any questions you do not wish to answer or to leave at anytime.
- For more information about risks and side effects, ask one of the researchers.

### **Are there benefits to taking part in the study?**

There will be no direct benefit to you from participating in this study. However, the information that you provide may help health professionals better learn more about the organ donation process in the African American community.

### **What other choices do I have if I do not take part in this study?**

You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no penalty to you.

### **Will information about me be kept private?**

We will do our best to make sure that the personal information gathered for this study is kept private. However, we cannot guarantee total privacy. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

Organizations that may look at and/or copy your research records for research, quality assurance, and data analysis include:

- The University of California
- UCSF School of Nursing research faculty and graduate student researchers may review de-identified research records for data analysis and teaching purposes.

### **What are the costs of taking part in this study? You will not be charged for your participation in the study. Will I be paid for taking part in this study?**

In return for your time, effort and travel expenses, you will receive a \$10 Starbucks gift card for the first interview and a \$15 Starbucks gift card if a second, follow-up interview is conducted taking part in this study

### **What are my rights if I take part in this study?**

Taking part in this study is your choice. You may choose either to take part or not to take part in the study. If you decide to take part in this study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you in any way. You will not lose any of your regular benefits.

### **Who can answer my questions about the study?**

You can talk to the researcher about any questions, concerns, or complaints you have about this study. Contact the researcher Debra Law at 408-307-6743.

If you wish to ask questions about the study or your rights as a research participant to someone other than the researchers or if you wish to voice any problems or concerns you may have about the study, please call the Office of the Committee on Human Research at 415-476-1814

### **CONSENT**

You have been given a copy of this consent form to keep.

**PARTICIPATION IN RESEARCH IS VOLUNTARY.** You have the right to decline to be in this study, or to withdraw from it at any point without penalty or loss of benefits to which you are otherwise entitled.

If you wish to participate in this study, please read each sentence below and think about your choice. After reading each sentence, put your initials in the “Yes” or “No” box.

1. \_\_\_\_\_(date). I will participate in an interview that will last one or two hours and will be recorded.

Yes

No

2. \_\_\_\_\_(date). I agree to be contacted later for questions or another interview.

Yes

No

\_\_\_\_\_  
Date

\_\_\_\_\_  
Participant's Signature for Consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Person Obtaining Consent

Appendix 4: Demographic Questionnaire

Participant # \_\_\_\_\_

1. Age \_\_\_\_\_
2. Gender \_\_\_\_\_
3. Highest level of education
  - \_\_\_\_\_ High school diploma/ GED
  - \_\_\_\_\_ Some College
  - \_\_\_\_\_ Associate's degree/Trade School
  - \_\_\_\_\_ Bachelor's degree
  - \_\_\_\_\_ Graduate degree
4. Annual income (range)
  - \_\_\_\_\_ \$20,000 or less
  - \_\_\_\_\_ \$21,000-\$30,000
  - \_\_\_\_\_ \$31,000-\$40,000
  - \_\_\_\_\_ \$41,000-\$50,000
  - \_\_\_\_\_ \$51,000-\$70,000
  - \_\_\_\_\_ \$71,000 or more
  - \_\_\_\_\_ Decline to state

Appendix 5: Literature Review

**Table 5.1**  
*Frequency of Code Names*

<b>Code Name</b>	<b>Number of Occurrences</b>
Altruism/Turning Death to Life	48
Breakdown	51
Clinician's Acknowledgement (or not) of LO's Personhood	25
Connection w/LO's Body/Organs	26
Decision-Making	130
Decision-Making: Time	5
Disease & Donation	13
Donor's Wishes/Intention	63
Organ Donation Request as an African American	16
-Staff & Caregivers	7
-Demeaning Communication	3
-Empathetic Approach	5
-History & Disregard	7
-Knowledge Regarding Race & Process	13
-No Prior Discussion	15
-Trust of MD/Process	11
Prior OD Knowledge/Experience/ End-of-Life Perception	57
Regrets/Changes	62
Respect/Disrespect	42
Role of Faith/Burial plans	48
The Narrative of the Loved One	51



Appendix 6: Organ Donation Requests

**Table 6.1**  
***Organ Donation Requests***

<b>Code &amp; Definition</b>	<b>Illustrative Quote</b>
Altruism- Turning death into life for recipient(s).	<i>“Because of the violence of the situation and how she passed, we wanted to try to make something good out of something bad, something horrific.”</i>
Breakdown- When the call or notification was received about the LO’s illness or, impending death or passing	<i>He says, “I want to talk to you about donating[his] organs.” And I was like, I was still reeling from the fact that we were in this hospital and all the stuff we were already going through”</i>
Clinician’s Acknowledgement (or not) of LO’s Personhood- An acknowledgement of the LO’s personhood and or humanity independent of their potential as a donor.	<i>There was an aggressiveness that came forward to show no compassion, no sensitivity. It was more methodical of this is what we need.</i>

<p>Honoring the LO as a human instead of the sum of their organs, tissues, etc</p>	
<p>Connection w/LO's Body/Organs- A connection to certain or specific organs</p>	<p><i>And when they were like, "We want to take his retinas." And I was like, "I'm not going to take his eyes."</i></p> <p><i>Because I loved his eyes. And I always the color of his eyes. And I always thought that that was one of his great assets and features, were the color of his eyes</i></p>
<p>Decision-Making- The process, timing, and/or individuals involved in the decision-making process.</p>	<p><i>No, I think the fact that I might have had a heads up and knew the facts about African-American donation, only because the funeral home guided me. Otherwise, when they ask you about organ donation, they'll put all these facts in front of you and they're not even really listening because they're just wanting a yes or a no.</i></p>
<p>Disease &amp; Donation- Concern about eligibility to donor related to disease process(es)</p>	<p><i>So we found out he had passed away... I wanted to know what part of him can I donate and they said the eyes. ... they said because of the age, because of the extent that you know the other organs are not viable enough. So they said well we can always donate the eyes...</i></p>

<p>Donor's Wishes/Intention- Were the wishes known and/or communicated to family</p>	<p><i>If it would have been something that would have been discussed with me, I think I would have maybe had an easier time with it.</i></p> <p><i>If it would have already been in writing, because I would have felt more reassured. Like it wasn't just ... You know, you kind of feel like the weight of the world is on your shoulders. I do feel that sometimes minorities do not feel that, you know, that's necessary. To leave things in writing.</i></p>
<p>Organ Donation Request as an African American- The segments of the request process unique to the African American families.</p>	<p><i>It's very different for African American family, ...a lot of people, my family members, or African Americans in general, it's like, I came into this world with this body, I'm going out with this body. Um, I just recently had an aunt that passed away. And I had mentioned to them about donating, it was like, no, no, we're not cutting Mom up.</i></p>
<p>Prior OD Knowledge/Experie nce/ End-of-Life Perception</p>	<p><i>I don't know much about organ donation except, when you renew your license, there's a question ... There's an opportunity for you to make that determination. Maybe I ought to do some more research ... Are they sold? Or is there someone gaining money from this? Are we saving lives? What's going on?</i></p> <p><i>How can I be sure that what is being said is going to be carried out.</i></p>

<p>Regrets/Changes- Regrets and /or advice to other families experiencing organ donation request.</p>	<p><i>I would love for them to have given us enough time to accept the situation, but looking in hindsight, they had to do it, because you have to get those parts out. You have to put them while they will still be of use, so I think all families should sit down with all of their loved ones, and I think that they should talk about this. This should be an important issue. There should be something that's put on paper.</i></p> <p><i>I just think the Afro American race should be more educated about it. This is what you want your family to accept.</i></p>
<p>Respect/Disrespect- Respondent's perception of actions, interactions or speech described as respectful or disrespectful</p>	<p><i>Because she showed such respect by acknowledging my pain first and giving her condolences and giving me the respect to ask permission of am I ready to discuss it? I felt she acknowledged my pain.</i></p> <p><i>I felt like she gave the power to decide. She didn't take power from me.</i></p>
<p>Role of Faith/Burial plans-. Beliefs about organ donation based on faith. Burial concerns</p>	<p><i>You know, one of the concerns was how her body would look. I was new to that type of stuff.</i></p>

<p>related to organ donation.</p>	<p><i>The mortuary actually told me, you know, nothing would show. I thought maybe if they were gonna open her up in the head, or you know, what her hair would like. You know, because we had an open coffin, and everything, open viewing. You know, obviously, there were no problems. That was one of my areas of concern.</i></p>
<p>The Narrative of the Loved One- Continuity or congruence with the story of who the LO was as an individual and the relationship (constituted by relationship and situation in the world).</p>	<p><i>Like I said, my mom was always a very spiritual, you know, strong person. I know, in my heart, that she would have been pleased. You know, in some shape or form, life going on.</i></p>

Appendix 7: Literature Summary

**Table 7.1**  
*Literature Summary Table*

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Andrews et al. (2012)	Cluster randomized To test the effectiveness of interventions to increase organ donation among members of Black churches as evidenced by registration in the state's donor registry	1336 Black adults from 22 African American churches in Michigan	Church members were trained as peer leaders for healthy eating or organ donation groups	Intervention and control groups did not show significant difference on posttest attitude scales. With the exception of change in attitude, lay leaders in Black churches can increase donor registration.	Randomization was appropriately performed. Only 74% of the cohort was reached for follow up one year later.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Baughn et al. (2010)	To increase understanding of the interpersonal interaction between procurement coordinators and families during the organ donation discussion with. To assess the influence of the race and gender of the coordinator and the race of the potential donor's family. A quantitative descriptive study	17 procurement coordinators in the Midwest	33 interactions between standardized patients portraying family members and actual procurement coordinators were videotaped. Nine psychology students viewed the videos and rated the procurement coordinators and families using two tools	African American procurement coordinators expressed a more positive affect when interacting with the African American family than the white family and the opposite was true for white procurement coordinators	The sampling strategy was not relevant to address the study. The sample was not representative of the target population.
Boulware et al. (2002)	Cross-sectional. To examine disparities in donor behavior: race and gender differences in willingness to donate blood and cadaveric organs	485 respondents: 114 African American females; 46 African American males; 110 white females; 69 white males	Telephone survey of Maryland households contacted via random-digit dialing.	Controlling for all factors unable to explain differences in willingness for African American females and white females or willingness to donate for African American men.	The sample is not representative of the target population. The sample only included African Americans and whites. The measurements are appropriate for the purpose of the study.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Brown (2012)	10-item survey to explore the five common barriers to organ donation in African Americans	A non-random convenience sample of members of an African American sorority and congregants of an African American church in Philadelphia (N=55).	Respondents completed an anonymous 10-item (9 quantitative questions and one open-ended question) survey online about organ donation perceptions	The majority of respondents reported reservations to organ donation related to mistrust.	The participants are not representative of the target population. There was only a 78.6% return rate. The tool was not validated or reliability tested. The study is a pilot study designed to identify strategies to increase organ donation intention in African Americans.



<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Dodd McCue & Tartaglia (2007)	To examine if there are significant differences between African American families that consent to donation compared to those that do not. Retrospective non-experimental study	120 African American potential donor cases	A random sample of 120 African American potential donor cases(32 consent and 88 nonconsent cases) from an academic medical center. Variables of interest: next-of-kin relationships, family interactions, knowledge of donor wishes, family initiation of the donation discussion and satisfaction with the donation process. Variables measured using binary scales	Statistically significant differences between African American consent and nonconsent cases.	The sampling strategy is relevant to address the question of consent and nonconsent. The statistical analysis of the variables of interest is appropriate.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
DuBay et al. (2018)	To inform future interventions designed to increase the number of African Americans becoming registered organ donors (ROD) at the Department of Motor Vehicles (DMV). Quantitative phone survey	N=155	Alabamians who had visited a DMV over a 3-month period were recruited to answer questions about their decision to become a registered organ donor at the DMV.	Of the n=122 who chose to become a ROD 41 made the decision during the visit to the DMV. Nearly 85% were interested in learning more about organ donation while waiting via digital signage using input from organ donors, transplant recipients and healthcare providers. Altruism, and encouragement from family and friends ranked highest for encouraging African Americans to become ROD.	Strength(s): Sample size. Can inform future interventions to increase the number of African Americans who become RODs. Weakness(es): Sample was not representative as it only included licensed automobile drivers at one DMV office.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
DuBay et al. (2019)	Explore the experiences of familial notification of recent African American registered organ donors (ROA) and identify potential barriers to the process of notifying family.  Qualitative focus group	N=50	Common themes were analyzed and categorized using recordings and transcripts from the focus group.	The themes identified: motivation for notification, conversation and promotion of familial notification.	Strengths(s): Strategies to educate and facilitate the discussion were identified. Weakness(es): Small sample size

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Flemming et al. 2020	Understanding of the decision-making process of organ donation in African Americans.  Quantitative questionnaire	N=1339	Residents of 16 zip codes with the highest percentages of African American residents, using Census data and the state donor registry.	Questionnaire measured decisional balance (pros/cons) related to organ donation, self-reported donation intentions and demographic information.	Pros were more strongly linked to donation intentions than cons Strength(s): Large sample size. Results can inform interventions to increase donation. Weakness(es): Sample is not representative. Causality cannot be assumed. Self-reporting may not align with actual behaviors.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Hartwig et al. (1993)	Effect of organ donor race on health team procurement efforts. Retrospective chart audit	152 patients	Retrospective chart review conducted at a regional trauma center. Charts were reviewed for donor identification, donation request and consent or refusal.	Before and after controlling for cause of death, African Americans were 2.4 times more likely than whites to not be identified as potential donors	The use of descriptive statistics to analyze all demographic data was appropriate. The sampling was appropriate as the trauma center serves approximately 50% African American patients. Confounding variables were accounted for in the analysis stage.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Jacob Arriola et al. (2007)	To describe and understand the attitudes, beliefs and experiences towards organ and tissue donation among African American clergy Mixed methods study using focus groups and questionnaire	26 African American clergy in Atlanta, GA	4 clergy focus groups followed by a questionnaire	The African American clergy though generally supportive of organ and tissue donation have reservations regarding the inequities in the allocation of organs	In order to enhance qualitative findings a questionnaire was used to provide a comprehensive understanding of the phenomenon. The different components of the study are effectively integrated to answer the research question.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Jacob Arriola et al. (2008)	Cross-Sectional. To explore the relationship between knowledge and African Americans' donation decisionmaking .	425 Black adults from 9 churches in metropolitan southeast US	Self-administered questionnaire. Data collected were part of a larger study	The relationship between donation knowledge and donation intentions in African Americans is complex and may depend on specific type of knowledge being measured	The sample is relevant to the target population. The statistical analyses used are appropriate for the design and question. The sample is not representative of the target population as it does not include African Americans who do not attend church.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Kernodle et al. 2021	Examine changes in deceased organ donation ratio in people of color in the US over time.  Population-based cohort study	N=141,534 deceased donors and 5,268,200 potential donors	Data used from Jan 1, 1999 through December 31, 2017 from the Scientific Registry of Transplant Recipients to quantify the number of actual deceased organ donors. Data were analyzed from December 2019 to May 2020	Black individuals donated at on 69% the rate of White Findings: Among Blacks, the donation ratio increased 2.58 fold from 1999 to 2017, significantly greater than the 1.60% increase in Whites. The gains observed over time in Black individuals are attributed to the population being the primary targets of study and intervention.	Strength(s): Large sample size using national mortality data. Weakness(es): Mortality data could not reveal whether there were underlying causes of death may or may not have affected the eligibility to donate. Race/ethnic categories have changed over time and are social constructs.



<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Law & McNiesh (2012)	To explore the barriers to organ donation in the African American communities of California Nonexperimental, descriptive, cross-sectional design	144 African Americans in California	Questionnaire completed online and paper, by participants who were recruited via social media, email and 2 predominantly African American churches	The barriers to organ donation in previous studies performed in other regions of the country are not representative of the respondents in California	Unable to assess nonresponse bias. The sampling strategy is relevant to address the research question. The variables are clearly defined and accurately measured.
Morgan et al. (2008)	To understand the ways in which self-identity and experiences of the Caribbean community of south London shaped their perceptions and attitudes to kidney donor registration and may explain the low rates of deceased donation. Qualitative study	14 patients from a London general practitioner's office	Data collected through in-depth interviews	Death may alter or intensify the way people choose to define themselves. Identity and belonging may affect minorities' willingness to consider cadaveric organ donation.	The qualitative approach is appropriate to answer the research question. There is coherence between qualitative data sources, collection, analysis and interpretation.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Morgan & Cannon (2003)	Close the knowledge gap about organ donation among African American. Quantitative surveys	300 African American adults sample	310 surveys were distributed by New Jersey NAACP chapter presidents completed and collected	Knowledge items were answered correctly 33%-78%. Belief that the allocations system is inequitable and that donors pay extra medical bills were held by the nondonors. The information sources reported by African Americans willing to donate were more likely to include family members.	310 surveys were distributed and completed but the sample size is 300 without any explanation for the difference in numbers. The statistical analysis is appropriate to answer the research questions. The sample is representative of the target population.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Morgan et al. (2016)	Identify barriers to organ donor registration and consent among Black, Asian and minority ethnic(BAME) groups. To develop interventions to increase consent. Focus groups	228 focus group participants and 17 bereaved family members in addition to 173 healthcare professionals and organ donation committee members in London	Three-part study with systematic reviews about organ donation barriers and interventions, focus groups followed by qualitative interviews with ICU & ER staff and bereaved family	Attitudinal barriers identified. Hospital staff not confident supporting ethnic minority families. Training developed to increase confidence in cross-cultural communication.	Only families who consented to donation were permitted. Unable to determine demographics of participants Results not generalizable to Americans.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Quick et al. (2012)	Explore how response rates to organ donation materials could be increased. Focus groups	98 high school seniors. African American (n=39), Hispanic (n=27) and White(n=32)	Fourteen focus groups were conducted over a 10-week period with high school seniors. Schools selected had relationships with organ donation liaison	African American, Hispanic and White high school students are largely unaware of the need for organ donors, and unfamiliar with how to join the FirstPerson Consent Registry. Participants identified more barriers to joining the registry than benefits.	A grounded theory approach was used to inform the analysis and enhanced the understanding of the Health Behavior model's influence on the interpretation of the themes. Quotes provided justify the themes

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Reinhart & Lilly 2020	Identifying barriers and strategies for African Americans and organ donation.  Nominal group technique (a type of focus group)	N=50	Participants were placed in seven groups over a 5- month period. Each session was audio and visual recorded for transcription purposes. Participants ranked barriers and potential strategies for increasing organ donation among African Americans.	Findings: Major barriers identified include lack of knowledge, myths about donation and mistrust of the medical community. Potential strategies included educational campaigns, testimonials, statistical messages, and community involvement.	Strength(s): The nominal group technique used is known to generate more equal participation among group members. Weakness(es): The small sample size. The nominal group technique did not allow for follow-up questions to delve deeper into the responses.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Resnicow et al. (2010)	To test the efficacy of using hair stylists as lay health advisors to increase organ donation among African American clients. Randomized, controlled intervention trial.	2,249 Blacks and 261 nonBlacks	Hair salons in Michigan randomly assigned to the Organ Donation or Usual Care conditions. 34 stylists who participated in the control group and 34 in the intervention group, were given 50 client packets with one month to enroll 50 clients	Clients of hair stylists trained to provide brief motivational intervention for organ donation were approximately twice as likely to enroll in the donor registry as comparison clients.	There was no pretest to establish whether the groups were comparable at baseline. Sealed envelopes were used to ensure allocation concealment thus ensuring that randomization was performed appropriately.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Robinson et al. (2014)	<p>Explore the relationship between religiosity, spirituality and cadaveric organ donation.</p> <p>Cross-sectional research design</p>	505 participants who identified their religion as Christian.	Community health advocates who had demographic similarities to the target population were trained and asked to recruit participants who self-identified as Black and 18 years of age or older.	Two-thirds of participants were willing to donate organs after death, and 46% had expressed their written donation intention via driver's license or a donor card. Only religious norms were significantly negatively associated with the written expression of donation intentions.	The target population and inclusion and exclusion criteria were clearly described. Confounders such as participants overestimating or underestimating their responses to donation religious attitudes/beliefs were not accounted for in the analyses.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Robinson & Jacob Arriola (2015)	Explore the construct of trust. Guided by three hypotheses: Trust in the healthcare system is associated with positive attitudes toward donation; Trust in the allocation system is associated with positive attitudes toward donation. 3. Physician trust is associated with positive attitudes re: donation.	585 African American adults in Atlanta, GA	Participants completed a survey using a total of 4 scales.	Trust is critical to organ donation decision-making and should be measured using a multidimensional approach.	Statistical analyses to measure trust were appropriate. Sample size was large and relevant to address the research question.



<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Rumsey et al. (2003)	To determine the influence of knowledge and religiousness related to attitudes about organ donation. Quantitative design.	190 undergraduate students enrolled in a general education course at a midwestern university	The Organ Donation Attitude Scale (ODAS), a 20-item questionnaire was administered	Individuals who rated themselves higher in religiousness were more likely to be less accepting of organ donation.	The sample was not representative of the target population and the inclusion criteria were not clearly stated. The measurements were appropriate and the ODAS was validated and reliability tested.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Russell et al. (2012)	Understanding the association between distrust in the healthcare system and written and verbal expressions of donation intentions among African Americans. Cross-sectional research design.	585 African American adults in Atlanta, GA.	Data from this study were collected during the baseline assessment of a larger study that sought to test the effectiveness of a culturally-sensitive organ and tissue donation intervention for African Americans. Participants completed a 98-item survey.	Distrust in the healthcare system varies in the way that it is associated with donation intentions.	The variables were clearly defined and accurately measured. The statistical analyses were appropriate for the cross-sectional design of this study.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Salim et al. (2010)	To examine the impact of race on organ donation rates in Southern California. Retrospective design	Data from 1776 actual donors over the course of 4 years.	The records of patients referred to a Southern California organ procurement organization between the years 2004 and 2008 were reviewed. Data was collected regarding the number of referrals for organ donation, eligible deaths, eligible donors, type of donor, organs procured per donor and organs transplanted per donor. Age, race, and gender were also recorded.	Race did not affect organ transplanted per donor and was not an independent predictor of organ yield after controlling for other factors.	There was a clear description of inclusion criteria. The statistical analysis was clearly stated and appropriate for the research question.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Siminoff et al. (2003)	To compare the organ donation request experiences of Black and white patients' families with the hope of identifying interventions to better inform consent rates among Blacks. Mixed method design	The medical records of 11,560 deceased patients were reviewed. 415 families were interviewed	Data were collected for 5 years on all patients eligible to donate in nine hospitals in Pennsylvania and Ohio. Also, family members who played a role in the donation decision were invited to be interviewed .	White families were more likely to be correctly perceived as receptive to donation and transplantation.	The data gathered by both interviews and chart reviews provided a more complete picture of the research question. Descriptive statistics were appropriate and clear. The interview questions were based on theoretical considerations.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Spigner et al. (2002)	<p>Are there ethnic differences in knowledge and opinions among urban high school students?</p> <p>Quantitative survey</p>	247 students in 13 separate classrooms	A 35-item questionnaire was administered to 247 students in three schools during regular classroom sessions	<p>More than 50% of the students did not know the correct answers to 13 of the 16 questions on factual knowledge. African American and Asian American students were significantly less likely to want to become organ donors when compared to non- African Americans and non-Asian Americans.</p>	<p>The self-administered survey is appropriate for answering the research question. The statistical analyses are appropriate to answer the research question and design. It is unclear if any students declined to participate.</p>

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Terrell et al. (2004)		107 Black students attending a white ,public university in the Southwestern United States.	Black students enrolled in a psychology course were asked to complete 3 different inventories and a background questionnaire. The surveys were designed to measure altruism, cultural mistrust and organ donation knowledge.	Participants with low scores on the altruism tool and high scores on the cultural mistrust tool were less willing to consent to donating their organs. Females and individuals with high mistrust scores were less willing to permit the recovery of organs from relatives.	Researchers reported that 10 students were excluded because of incomplete information. Another 3 female students became upset while completing the questionnaires and could not continue. The measurements were clearly defined and reflect what they are supposed to measure.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Williamson, Bigman, & Quick (2019)	Focus groups discussions to gain understanding of African Americans' medical mistrust regarding organ donation.	N=62	Five focus groups were conducted using semi-structured interviews which were recorded and transcribed	Findings: Four categories of medical mistrust beliefs: societal distrust, distrust of general institutions, distrust of medical institutions, and organ donation-specific medical mistrust. Medical mistrust beliefs were thought to be the result of personal experiences, interpersonal communication and exposure to the media.	Strength(s): Focus groups allowed participants to give detailed and in-depth answers. Weakness(es): Majority of participants were African American women from Chicago, therefore, the results are not generalizable.

<b>Authors</b>	<b>Purpose &amp; Design</b>	<b>Sample</b>	<b>Methods</b>	<b>Findings</b>	<b>Strengths and Weaknesses</b>
Vranic, Ma, & Keith (2014)	Examining the role of minority geographic distribution in waiting time for deceased donor kidney transplantation.  A cohort study	All registrants for kidney transplant between 2004 and 2007 (N=126094)	The Scientific Registry of Transplant Recipients database's candidates were analyzed for waitlist time, race and geographic distribution	Geographic location of waitlisted candidates is the most important contributor to racial disparities in waiting times for deceased donor kidney transplantation.	The participants are representative of the target population. The statistical measurements are appropriate to answer the research question.



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