

**THE EXPERIENCE OF AFRICAN AMERICANS WHO HAVE CHOSEN TO BECOME
ORGAN DONORS DESPITE TRADITIONAL FAMILY VALUES: A CASE STUDY**

by

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Abstract

This qualitative case study was an examination of African Americans' experiences choosing to become a registered organ donor despite traditional, cultural, and family values that oppose becoming an organ donor. African Americans have traditionally been reluctant to donate their organs, but as a population, they exhibit a higher need for organ transplants compared to other races and would benefit from a more significant number of African Americans becoming organ donors due to having compatible blood types and tissue markers. This study answered the research question "How do African Americans who have chosen to become registered organ donors describe their experience, despite traditional family values?" The Stake (1995) model of case study research was used for the study. The sample consisted of nine African Americans who met the research eligibility requirements and were willing to participate in the study. The resulting data revealed the following relevant themes: (a) family opposition, (b) communication with family is important, (c) goodness as motivation/being helpful, (d) other positive motivation, (e) outreach to community, (f) negative motivation as part of experience, (g) lack of trust in the medical system, and (h) decision making.

Dedication

This dissertation is dedicated to my family. You have supported me through all of my endeavors. Mom, Hannah L. Jackson, you always believed in me even when I was unsure of myself. You would not allow spinal meningitis to cause a learning deficit, nor the teacher that slapped me for reading, to be an excuse or to cause limitations and stand in the way of my success. To my aunt, Julie B. Tilford, thank you for always supporting me.

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CHAPTER 1. INTRODUCTION

Background of the Study

Organ transplants have been lifesavers for those who suffer from organ failure. However, each year in the United States, the number of people needing an organ significantly outweighs the number of available organs. According to the U.S. Department of Health and Human Services (DHHS; 2019), a person is added to the transplant list every 10 minutes. Approximately 95 transplants take place every day, and one person who donates all of their organs can save up to eight different lives. Many lives can be saved if more people opted to become organ donors. However, currently, of the 95% of people who are reported to support organ donation, only 54% are registered donors (DHHS; 2019). In addition, barriers, such as a lack of knowledge regarding organ donation needs, limited awareness of the transplantation process, a lack of trust in the medical system, fear of what might happen if the organ donation card is signed, racism, existing attitudes and religious beliefs all influence a person's decisions as to whether to become a donor or not (Robinson, Klammer, Perryman, Thompson, & Arriola, 2014).

According to the DHHS (2019) organ donation statistics, 83.4% of the people on the national donor registry are awaiting a kidney transplant. Of that number, 28.8% are African Americans. In 2018, a total of 36,528 transplants were conducted; of that number, African Americans represented 20.6%, Whites represented 55.2% and Hispanics were represented with 16.4% of all organ transplants conducted that year.

African Americans have traditionally been reluctant to donate their organs (Minniefield, Yang, & Muti, 2001). African Americans suffer disproportionately from high blood pressure and diabetes compared to the overall population, and both of these health problems can cause damage either to the kidneys or other organs (Martins, Agodoa, & Norris, 2012). Although African Americans make up 13% of the overall population in the United States, they represent 28.9% of the more than 113,000 people on the national waiting list to receive organ transplants (DHHS, 2019). While organs are not distributed according to race, and people of different races do regularly match as donors and recipients, all people waiting for an organ transplant would have a better chance if there were significantly more organ donors from a broader range of racial or ethnic backgrounds (DHHS, 2019). Individual antibodies and markers are significant when matching a donor to a recipient (Zachary & Leffell, 2016). African Americans have a better chance of organ matches and successful transplants if received from other African Americans (Silva et al., 2019).

Despite the very high demand for organ transplants, the African American community in the past has been reluctant to donate organs (Morgan, 2006). Some of the reasons for this reluctance include family and cultural values that mitigate against organ donations, fear of the procurement process, religious beliefs, and prejudices against bodily mutilation (Morgan, 2006). Mistaken beliefs and attitudes of African American individuals towards the process of organ donation have also been noted as significant barriers. Finally, the high incidence of health conditions that afflict members of the African American community reduce the number of suitable donors (Pouraghaei et al., 2015).

The African American community urgently requires more community members to become organ donors. Thus, there is a need to break through whatever barriers exist to organ donation. As several barriers appear to be cultural, an examination of African American families and their beliefs, practices, and attitudes may provide a gateway to new insights into the reasons they have been reluctant to become organ donors. According to Kerr and Bowen (1988), every family is a system that influences how people think and how they emote passing down beliefs and values from generation to generation. The traditional values of a family are passed down to each generation through conversation and actions within the family unit, and a family's beliefs, values, fears, and patterns are often transmitted through family conversations (Kerr, 2000). When deciding to become an organ donor, African Americans step outside of the family norm to act, solely based on personal altruistic views (Robinson et al., 2014). When such an action takes place, a conflict may occur between traditional family values that mitigate against organ donation and the person's decision to donate organs.

The present study was an examination of the conflict that may occur when a person has chosen to become a registered organ donor, while their family remains against the practice of organ donation and, as a result, may not be supportive of the family member who decides to donate organs. When a family member develops a sense of intellectual independence and begins to think outside of the family norm, differentiation occurs. The individuals in question begin to make decisions based on their thoughts and beliefs, even if they contradict family beliefs and values (Sohrabi, Asadi, Habibollahzade, & Panaali, 2013). In such cases, altruistic decisions that may violate preexisting family norms become possible, and such behaviors are supported by

research that indicates people want to be altruistic and pure altruism does genuinely exist (Batson, 2011).

Yousefi, Roshani, and Nazari (2014) reported that altruism is the most significant element in organ donation; however, the immediate family is the decision maker when it comes to final organ donations of a loved one. Therefore, it is of importance to consider the whole family unit, and specifically, the family values (values passed down from generation to generation) when examining decisions whether to donate or not donate organs. These values, in the case of the African American family, appear to be problematic in the context of supporting organ donation. As previously noted, traditional family values related to cultural concerns regarding bodily disfigurement, family religious values, a lack of knowledge of the loved one's wishes upon death, and lack of trust of the medical system among African Americans all weigh on family support regarding organ donation (Robinson et al., 2014).

Need for the Study

The U.S. Department of Health & Human Services Office of Minority Health (OMH, 2016) reported that African Americans represented a disproportionately high percentage of the total number of potential organ recipients on the transplant waiting list. The situation has not improved since. At the time of this dissertation, 28.9% of the more than 113,000 people on the national transplant waiting list were African American, despite representing only 13% of the overall population (DHHS, 2019). Statistics suggest that the paucity of registered African American donors remains unchanged (Siegel, Navarro, Tan, & Hyde, 2014). Scholars, researchers, and practitioners continue to be perplexed by people's overall attitude toward organ

donation and donor registration intentions. Although there is a positive attitude among individuals regarding organ donations, registration remains at low levels in this population.

Research about African Americans highlights ongoing cultural and trust issues with organ donations (Novotney, 2011; Robinson et al., 2014; Russell, Robinson, Thompson, Perryman, & Arriola, 2011). Russell et al. (2011) noted that additional research was needed to determine how “distrust in the health care system impacts different types of organ donation intentions” (p. 45). Additionally, Long et al. (2012) researched the timing of organ donation and the way individuals discussed their desire to become organ donors and noted that more research was required into effective written intentions to donate.

The literature on organ donations indicates that cultural, religious, and family issues can impact African Americans’ propensity to become registered organ donors. However, there appears to be a significant gap in the extant literature regarding the role of traditional family values and organ donation intentions among African Americans. No study in the extant literature examines the role of the family as a mediating factor in the transmission of both cultural and religious values related to organ donation and the experience of African Americans who have chosen to become registered organ donors in the face of family opposition.

Theoretical Framework

The theoretical framework for this study was a culturally informed approach to positive psychology and the moral development theories of Kohlberg (1958) and Gilligan (1982). The focus of the theoretical framework was on the moral dilemma of decision-making, as well as Bowen’s (1966) family systems theory. Kerr (2000) posited that family systems theory could be used effectively to assess the weight of a family’s influence when an individual decides to

become a registered organ donor. A culturally informed approach to positive psychology consists of focusing on the strengths and values of racial minority groups, which can positively influence the psychological well-being of the group (Chang, Downey, Hirsch, & Lin, 2016).

Agreeing to become an organ donor is related to Kohlberg's (1958) and Gilligan's (1982) work with the theory of moral development. Gilligan used the same concepts as Kohlberg; however, Gilligan explored the theory from a female perspective. In the context of Bowen's (1966) family system, the theory provides insight into the family as a unit and shows how researchers can explore how family functionality influences how an individual thinks and acts.

The theory of moral development includes three levels of moral reasoning: preconventional, conventional, and postconventional (McLeod, 2016).

Level 1 pre-conventional: the individual's morality is controlled externally, and the individual conforms to rules to avoid trouble or punishment for self. The individual, however, is still motivated by the desire to satisfy his or her personal needs. His or her decisions are made based on the risk of consequences or punishment. Individuals may not become an organ donor for fear of upsetting their family, though the decision to become an organ donor would be based primarily on one's self-worth or benefit.

Level 2 conventional: the individual wants to comply with social rules and is concerned with social conformity, the opinions of others, and obeying the laws. Favorable attitudes to organ donation are based on being a good person and doing what is right and on following the rules of social order. The individual may consider becoming an organ donor because there is a need, but has not signed the registration card and has concerns about how the family values organ donation.

Level 3 post-conventional: Decisions made based on the individual's ethical principles and possesses a more nuanced view of laws and rules in light of the need to accommodate broader societal issues. At this level of moral development, individuals may become a registered organ donor regardless of their family's wishes. Actions by the individual will be based on their best judgment as to the fitness of any given action based on how it satisfies his or her altruistic impulses to address society's broader needs even if their actions result in conflicts with their family's values (McLeod, 2016).

Purpose of the Study

The purpose of the present study was to examine how African Americans who have chosen to become registered organ donors in the face of opposition based on traditional family values describe their experience. The phenomenon under investigation in the present study was the experience of the African American participants who faced family opposition when choosing to become registered organ donors. As a result, the focus of the study was on the conflicts that occur in the lives of donors whose families have historically resisted or spoken out against organ donation. Past researchers have suggested that traditional family values are a significant consideration when an individual decides to register as an organ donor (Yousefi et al., 2014).

A qualitative multiple-case study proved to be the most effective approach to address the research question. Qualitative methods have been demonstrated to have the ability to provide in-depth and multidimensional descriptions of real-life experiences (Ponelis, 2015). Qualitative designs allow in-depth exploration of topics by allowing for the use of more detailed questions and exploration of how and why an event has occurred. This process of exploration of a topic is

further supported by the ability of qualitative research to include open-ended and general questions, in furtherance of the ultimate goals of the research.

Researchers have identified many factors that influence the decision to register as an organ donor. In the case of the African American community, many of these factors also mitigate against African Americans registering as donors (Novotney, 2011; Robinson et al., 2014; Russell et al., 2011). Family serves as a critical influence on individuals, and Yousefi et al. (2014) specifically noted the impact of traditional family values on the decision to register as an organ donor. As a result, the present study's examination of the experience of African Americans who have chosen to become organ donors against their families' wishes has the potential to significantly extend the scholarly understanding of the factors influencing organ donation among African Americans.

Significance of the Study

The issue of organ donation registration rates versus the demand for organs in the African American community is one public health issue of ongoing importance to both the African American and broader communities (OMH, 2017; Pouraghaei et al., 2015). As a result, the present study may be of significance to not only the wider community, but also to both the practitioner and professional communities. The present study also makes contributions to the scholarly community with its perspective on the family as a unifying factor, linking disparate causes of resistance to organ donation previously identified in the literature (Morgan, 2006; Novotney, 2011; Robinson et al., 2014; Russell et al., 2011).

Kohlberg's (1958) and Gilligan's (1982) moral development theories and Bowen's (1966) family system theory constituted the theoretical framework for the present study.

Furthermore, the present study's analyses utilized a culturally informed approach to positive psychology, which focused on the strength of racial minority groups. Such approaches have the potential to provide methodologies that positively influence the psychological well-being of communities or groups to which these approaches are applied (Chang et al., 2016). The present study and its results highlighted the importance of contributions from the field of general psychology in the dimensions of understanding both family systems and altruistic behaviors.

A better understanding of current African American family dynamics, including their psychological underpinnings, may support improved decision-making by practitioners (Chang et al., 2016). For example, when medical professionals consider end-of-life decisions, the insights provided by the present study may assist in developing more effective communication with family members and decision makers. Counselors may also find the present study's results useful as guidance when discussing the decision to become an organ donor with young people and their families. Also, as psychologists who work to change the misconceptions surrounding organ donation. The present study may assist in broadening the understanding of traditional family values and the role they play in decision-making when one has chosen, as an African American, to become a registered organ donor. Finally, the government may find the present study's findings of use in the creation of more effective advertising materials for the Department of Motor Vehicles' organ donation outreach programs.

Many factors previously identified in the literature, such as religious beliefs, traditional family values, cultural prejudices against bodily mutilation, and distrust of the healthcare system, are factors directly or indirectly moderated by family perspectives on these issues. As a result, the present study's direct focus on the family provides a unifying perspective on the factors

identified in previous scholarship (Morgan, 2006; Novotney, 2011; Robinson et al., 2014; Russell et al., 2011). Thus, this study advances current scholarship not only by providing direct evidence of family conflicts generated by family members' decisions to become organ donors, but also a potential new prism through which to create a more unified approach to the analysis of the previously identified factors mitigating against registration as an organ donor by African Americans.

Research Question

The research question guiding this study was: "How do African Americans who have chosen to become registered organ donors despite traditional family values describe their experience?" The research question is exploratory, which is suggestive of a qualitative case study focusing on a real-life phenomenon. The research question directed the study by addressing the experiences of African American participants, the participants' decisions to become registered organ donors, and the conflict that may result based on their traditional family values. The study allowed the participants to reflect on their experiences and give detailed depictions of the experience to help understand the conflict, the concerns, and the complexity of their decisions to become registered organ donors in African American families that oppose the practice of organ donation. The definitive answers provided by the participants will help to explain the phenomenon and can be used to develop future hypotheses and proposals for additional research (Yin, 2014).

Definition of Terms

For this research, the following terms were used and are presented here to provide clarity and consistency for the reader:

African American. African Americans are American people with ancestral origins in Africa (Agyemang, Bhopal, & Bruijnzeels, 2005).

Family. A family is a group of people related by blood. A family is also described as an emotional unit that affects how people think and function by passing down beliefs and values for generations (Bowen, 1966).

Organ. An organ is a part of the human body that performs a specific function. Organs eligible for donation include but are not limited to blood, tissue, kidneys, heart, liver, lungs, and corneas (DHHS, 2016).

Organ donation. Organ donation refers to a medical process where a healthy individual gives an organ or part of an organ to a sick person experiencing organ failure. Organ donors do not receive compensation for their organs (DHHS, 2016).

Traditional family values. Traditional family values are family values or cultural values passed on from generation to generation within families. Traditional family values consist of beliefs, ideas, family's arrangement, attitudes, morals, standards, and rules that have been passed down from generation to generation regarding how a family operates (Stone, 1994).

Research Design

The selected methodology for the present study was a qualitative multiple-case study (Stake, 1995). According to Stake (1995), in such studies, the researcher should have an interest in learning about the subject to be studied as well as an interest in how the participants experience the phenomenon and describe their experiences. The function of a case study is to provide a well-rounded description of real-life experience and find explanations for the experience, which was the goal in the present study. In case study research, the researcher can

develop a relationship with the participants and the research based on shared professional interests (Ponelis, 2015). Furthermore, in a case study, data may be gathered from multiple sources (Stake, 1995).

The present study utilized an informal semi-structured interview process characterized by a conversational style based on a question and answer format (Stake, 1995). Participants were carefully selected to obtain interviews that would meet the stated goals of the research. When the interviews were completed, the researcher followed Stake's (1995) methodology and carefully reflected on what had been learned to identify initial impressions and discern any initial patterns that might develop from the data. Stake noted that "there is no particular moment when data analysis begins. The analysis is giving meaning to first impressions as well as final compilations" (p. 71). Thus, based on the researcher's initial impressions, reflections, and research materials, the researcher began by developing a detailed description of each case and its setting.

Creswell (2012), Stake (1995), and Yin (2015) agreed that in the matter of case study data analysis, it is important to be well organized to avoid becoming confused by the mass of unstructured and semi-structured data gathered for analysis. Data analysis involves several steps, including thoroughly probing, assessing, and organizing the data to perform a proper analysis. The following is a systematic description of the procedures taken to complete the data analysis process:

1. Describe the case.
2. Develop a direct interpretation of the case.
3. Aggregate responses by category to reach meaning.

4. Complete the within-case analysis.
5. Complete the cross-case analysis.
6. Conduct an interpretive review of the analyzed material and develop generalizations.

During the analysis, the researcher identified patterns in the data from which to generalize and, in turn, create structured meanings that were eventually developed into themes supported by participants' responses. Each participant's interview notes were annotated with the themes applicable to that interview. A final synthesis of the themes that were common to each case was performed, and then, generalizations were drawn from the synthesized themes.

Assumptions and Limitations

Assumptions

Stake's (1995) methodology of qualitative research is based on the constructivist and interpretivist paradigms in which the researcher collects and interprets the information obtained from the participants' experiences. These paradigms are compatible with this study's design and focus because the researcher obtained information about the participants' experiences and used quotes from their responses as data rather than relying on numbers and statistics. A constructivist approach to research is appropriate for this study because it involves investigating the reasons for people's beliefs, values, and actions to identify patterns or themes. An interpretivist approach to research is effective because multiple viewpoints can be obtained from a diverse group of people. The desire to uncover real meaning and to understand the experiences from a true perspective allows researchers to become a part of the study by immersing themselves in the research. According to Stake, assumptions in research consist of expecting the participants to answer the questions honestly and to accurately recall experiences of events from several years

ago. The four qualitative assumptions that were made are: (a) ontological, which is concerned with the nature of the reality where one may ask, “Is there a social reality?” “What is reality like?” “What are the different perspectives reported and developed?” (b) epistemological or learning about the world and diverse ways of knowing, in which the researcher determines what does or does not establish knowledge; (c) axiological, which means that the researcher not only includes his or her interpretation, but allows values to shape the discussions; and (d) methodological, which includes assumptions made by the researcher concerning the methods used in the study. A methodological assumption was that the researcher would ask the questions necessary to investigate the phenomenon of interest. This researcher asked the questions and allowed the answers to emerge without interruption. However, when necessary, the researcher would also adjust the questions as the interview progressed based on the guiding question. The researcher kept in mind that, according to Creswell (2012), each person experiences life and circumstances from a unique point of view and that similar situations can be lived and described differently by everyone.

Limitations

This study had some limitations due to restrictions on time, a small number of participants, and because it was not generalizable. In this multiple-case study research, the first limitation included the inclusion of a low number of participants from a limited geographical area. The study was conducted in a single metropolitan city in the southeastern part of the United States, with one participant contributing over the phone from another state.

An additional limitation in the present study was that the participants provided self-reported responses to questions on a sensitive topic that was emotionally charged. The emotional

nature of the topic meant that participants' responses were subject to magnified or underreported experiences of overcoming traditional family values when they chose to become a registered organ donor. The process of recounting emotionally charged experiences can be challenging, and participants may have had difficulty articulating their emotions, which also could have affected the findings. When research deals with a sensitive topic, participants can become tired, suspicious, or weary and drop out of the study, thereby creating time constraints and additional limitations within the interview process (Atieno, 2009). These limitations were taken into consideration in this research.

Organization of the Remainder of the Study

The second chapter is the literature review. The third chapter contains a description of the methodology utilized, followed by Chapter 4, which consists of the results of the research. Finally, the fifth chapter contains a presentation of the findings and conclusions.

CHAPTER 2. LITERATURE REVIEW

This chapter consists of a scholarly literature review associated with the topic of the experience of African Americans who have chosen to become registered organ donors despite traditional family values. Some African Americans step outside of the family norm to become registered organ donors, and when this happens, a conflict may occur based on traditional family values. However, what is not known is how African Americans who have chosen to become registered organ donors, despite traditional family values, describe their experience. A literature review was conducted to prevent duplication of existing work and to identify the gap in the research. Several areas of additional research resulted in the literature regarding barriers concerning African Americans and organ donations. However, literature about the scholarly intersection of African Americans, organ donation, and traditional family values offered limited information, indicating a need for broader research.

Traditional family values play an essential role in the decision-making process within a family unit. The Bowen family systems theory described the family as being hugely influential as a unit affecting how each member thinks (Bowen, 1966, 1978; Kerr & Bowen, 1988). Furthermore, according to Stone (1994), family values can be divided into five broad groups, which impact behavior, and consist of (a) attitudes towards roles in society, (b) attitudes regarding work, (c) rules and regulations about sexual behavior, (d) attitudes about religion, and (e) attitudes about race. Stone also notes that these five values reflect what is needed for members of the lower middle class to obtain self-respect and advance in the world, which is hard work, thrift, sobriety, self-discipline, delayed gratification, reliability, a sense of responsibility to the self, the family, and the society, and a competitive desire for one's children

to obtain an education and to succeed (Stone, 1994, p.70). The Theory of *Reasoned Action* (Fishbein & Ajzen, 1975) and *The Theory of Planned Behavior* ([TPB], Ajzen, 1991; Ajzen & Fishbein, 1980, 2005a) also examined family communication and its importance in decision-making. TPB was considered when looking at organ donation and an individual's intention to become an organ donor. TPB played an important role in a study by Dimo (2018), who reported that attitude and behavior helped to determine intention and purpose regarding behavior intention. The study centered around the debate of organ donations among Black South Africans. An intriguing fact in the study was that Black South Africans had some of the same fears, lack of knowledge, and negative attitudes regarding organ donations as African Americans in the United States. The lack of available organs is of concern not only in the United States but worldwide and is magnified by the lack of knowledge regarding the donation process. Fishbein and Ajzen (1975) explained how the relationship between one's behavior could contribute to a better understanding of behavioral intention. Batson (2011) stated altruism and empathy was just wanting to help someone step outside the traditional family value and become an organ donor.

Methods of Searching

The ProQuest Central, PsycArticles, Psychology database, Psych database, and PsycINFO databases were all used to search the following terms: *African-American, organ donations, traditional family values, African-American communication, altruism, moral development, and beliefs*. These keywords were used to locate the peer-reviewed research articles that comprise this literature review. The literature was examined to identify seminal works and articles that focused on problems surrounding African Americans and organ donations. An exploration of the literature uncovered a gap in research that focuses on the relationship between

African Americans, organ donations, and traditional family values. The literature on organ donations and African Americans indicated that there is an urgent need for African Americans to become organ donors, which is further supported by the ongoing lack of African American organ donors, according to the U.S. Department of Health and Human Services (DHHS, 2016).

Theoretical Orientation for the Study

The theoretical framework of the study is comprised of three theories: (a) the moral development theories of Kohlberg (1958) and (b) Gilligan (1982), which focus on the moral dilemma of decision making, and (c) the Bowen (Kerr & Bowen, 1988) family systems theory. The family systems theory considers the family as an emotional unit that affects how people think and behave, passing down beliefs and values for generations.

The theory of moral development (Kohlberg, 1958), which is comprised of six developmental stages, are clustered into three levels consisting of

- Level 1. Preconventional morality. Individuals may not become an organ donor for fear of upsetting their family, though the decision to become an organ donor would be based primarily on their self-worth or benefit.
- Level 2. Conventional morality. The decision is based on being a good person and doing what is right, following the rules for social order. The individual may consider becoming an organ donor because there is a need but has not signed the registration card and has concerns about how the family values organ donation.

- Level 3. Postconventional morality. The individuals view laws and rules as more accommodating to improve human intention or needs. Decisions are made based on their ethical principles. In this stage, they may go against the family's wishes (McLeod, 2016).

Six stages identify how moral development progresses from infancy to adulthood (a) infancy characterized by avoiding punishment; (b) the preschool stage, characterized by an attitude of what do I get from it? (c) conformity good attitude; (d) school-age authority law and order; (e) social contract teenage years; and (f) reaching the sixth stage of universal ethical principals' adulthood (McLeod, 2016). The stages are representative of how people develop moral reasoning. Additionally, justice can be considered a vital feature of moral reasoning (Hayes, 1994).

Gilligan (1982), a former student of Kohlberg (1958), expanded the study of moral development based on her "care of ethics," using female participants; she asserted that both sexes progress through the levels of moral development. The average female achieved level two (conventional morality), stage three where one begins to look at what others are doing, the girl child is behaving well to be seen as good (moral judgment). Moreover, the average male child may reach level two (conventional) stage four (law and order) with the possibility of reaching (post-conventional) stages. Gilligan presented a conflict that a girl experienced between self and others, resulting in the theory that girls develop morally differently than boys (Gilligan & Attanucci, 1988). Gilligan and Attanucci (1988) concluded that women focus on care and men focus on justice. Also, when real life dilemmas occur, people are concerned with care and justice for others as well.

The Bowen Family Systems Theory

The Bowen family systems theory was considered an inclusive theory of family dynamics and function (Bowen, 1966, 1978; Kerr & Bowen, 1988). The family system theory also gives insight as to why conflict may have possibly developed when one stepped outside of the family for altruistic purposes. The family systems theory further emphasizes the human behavior aspect by viewing the family as an emotional unit that affects the thinking and behaviors of the individuals within the family unit for generations (Kerr, 2000). According to the theory, the family has a profound connection between generations, “people are born and die, but a family’s past lives in the present” (Kerr, 2000, p. 1). The family systems theory of human behavior indicates that the family uses systematic thinking within the unit to define connections and communications (Kerr, 2000). The individual child within a healthy family unit develops a sense of independence with the ability to think logically and make sound and emotional decisions that influence family dynamics. This is referred to as differentiation and is defined as the gradual release process of the family’s emotional dysfunctions when one looks at one’s self within the family unit as an individual, active participant, without placing the blame on others (Sohrabi et al., 2013).

People who are differentiated may have clarity about themselves, which allows them to choose a direction for their own lives, to independently make personal decisions with logic, wisdom, and emotional control (Sohrabi et al., 2013). In contrast, a non-differentiated person dependent upon the family unit may have no individual identity and may harbor psychological problems and anxieties. Non-differentiated persons found independent decision making difficult and may have made decisions dependent upon the family (Brown, 1999). Bowen (1988) believed

that there was an instinctual power that converted and developed a child into a person able to make sound decisions, be engaged in thought, and maintain emotional control or action within society and that this power is what drives a person toward differentiation. Bowen's theory also indicates that this instinctual power simultaneously compels the child and the family to support the emotional family ties. As a result, there is no real separation or remarkable difference regarding the differentiation within the family unit (Brown, 1999).

In combination with Bowen's theory, it is important to consider family communication and how the family discusses choices. Family communication has been and will remain, an intricate part of the organ donation process (Morgan, 2004). The way the family communicates, and whether the altruistic individual has communicated his or her wishes to the family becomes known when the family has been asked to donate the organs of the deceased loved one, as the opinions of family members, their knowledge of the process, and their willingness to donate organs play an essential role. People who have talked with family about their donation intentions and received positive support are the individuals who sign their donation registration cards. In these cases, the family is less likely to have an issue with the procurement process regarding the donor's intentions (Morgan, 2004).

Long et al. (2012) applied an interpretative phenomenological analysis in their qualitative study to determine how African Americans communicate their decision to become an organ donor to their family members. The researchers asked African American families about their knowledge, awareness, and commitment to organ donations. Twenty families participated in interviews that gathered information on how African Americans communicated their decision to become organ donors by answering a series of eight questions. The interview procedure began

with general, informal conversations with the family. Then, it proceeded with participants being asked to select an index card with questions to lead the discussions. The questions ranged from knowledge of the donation process, whether participants were registered donors themselves, and how their family members felt about their organ donation decisions. The results from the reports revealed that African Americans receive information about organ donations through passive methods, such as popular entertainment, community organizations, and literature provided by the motor vehicles department when receiving or renewing their driver's license. Statistically, African Americans are reluctant to donate, and it was found that when an African American has decided to become an organ donor, communicating their decision to family members was reported to evoke fear and could be problematic. Furthermore, the communication of the desire to donate is needed. Without the additional posthumous consent of the family, organ procurement by some agencies will not be processed despite having a donor registration card on file.

The examination of Long et al.'s (2012) study is relevant to the current case study. The current research examined the experience of African Americans who decided to become organ donors, despite traditional family values. The similar topic of deciding to become a registered donor against the family's wishes, then having to communicate the decision to the family, makes Long et al.'s work influential to the current research. In contrast, this research had a case study approach, while Long et al.'s study was an "interpretative phenomenological analysis as a tool to understand ways African American families discuss and make sense of their knowledge, awareness, and commitment of the organ donation process" (p. 555). Furthermore, the works of Bowen (1988) on family dynamics and communication and the Bowen family systems theory

provided additional insight into how the family thinks about decisions as a unit, and how one independent child within a family may make a decision, regardless of the family's beliefs.

Review of the Literature

In the examination of the literature, a few themes reoccurred, including the need for Africans-Americans to communicate their desires with the family of being an organ donor and that a child within the family unit differentiated could be the one that steps away from the family to become a donor (Brown, 1999; Morgan & Miller, 2002; Morgan, Miller & Arasaratnam, 2003; Quick, Morgan, LaVoie, & Bosch, 2014). The Bowen family theory was supportive of these themes. The different versions of altruism were a contrast between the research of Batson (2011) and Gintis, Bowles, Boyd, and Fehr (2003).

Regarding organ donations and the disproportionate numbers of African Americans on the waiting list, more work needs to be done to spread awareness of the need for organ donation. African Americans have a higher rate of success if the organs are donated by someone of the same race due to the aforementioned genetic markers (DHHS, 2016). To make a significant increase in donor numbers, clergy, social workers, and community educators must become involved in the education of organ donation to demystify the organ donation process (Reitz & Callender, 1993). There have been several studies conducted to provide insight into the lack of organ donor registrations, as well as the barriers for African Americans (Arriola, Perryman, Doldren, Warren, & Robinson, 2007). Researchers should continue to add to the body of literature about organ donation to answer questions and improve communication, which will hopefully result in increasing organ donations among African Americans, as well as improving the quality of life for those awaiting transplants. To begin to understand the communication

aspect, the Bowen family systems theory was applied. Several articles have been written and much extensive research has been conducted regarding African Americans and organ donations (Arriola et al., 2007; Ginossar et al., 2017; Kappel, Whitlock, Parks-Thomas, Hong, & Freedman, 1993; Morgan, 2006; Quick, LaVoie, Scott, Bosch, & Morgan, 2012; Reitz & Callender, 1993). A literature review was conducted to identify research into the factors that may be affecting organ donation numbers. Factors, such as fears of the organ donation process, mistrust of the medical system, lack of family communication, and lack of knowledge regarding the need for African Americans to donate organs were discovered. These barriers have contributed to a disproportionately high number of African Americans being on the organ donor waiting list for years.

The DHHS (2017) Organ Donor Registry confirmed that African Americans suffer from end-stage renal disease in significantly higher numbers than White Americans. However, they are far less likely to receive kidney transplantations (Siminoff, Burant, & Ibrahim, 2006). While African Americans make up 13% of the population, they represent 34% of the kidney waiting list, and 25% of those waiting for a heart (DHHS, 2017). A full 39% of the individuals on the national transplant waiting list are African Americans (DHHS, 2017).

Arriola (2017) confirmed in her study on race, racism exists in transplantation among African Americans. African Americans are less likely than White patients to want a kidney transplant even though a transplant would allow for a better quality of life. Additionally, she revealed racial disparities. African American patients are less likely to be referred for transplants and often will not complete the transplant evaluation process to be placed on the waiting list for an organ. She discussed racial disparities and how racism is relevant in discussions regarding

genetic and biological makeup with African Americans having different markers, attitudes of the patients and whether they will follow up on post-transplant medication and procedures, socioeconomic status, and for-profit dialysis clinics wanting to keep patients on dialysis because of Medicare payments. Furthermore, Arriola asserted that racism is progressively being connected to the central cause of racial/ethnic health disparities among African Americans that obstruct access to health care resources and knowledge. Novotney (2011) stated that many African Americans express a fear of donating organs due to a lack of knowledge surrounding the process and an underlying belief that doctors would allow them to die solely for the benefit of harvesting their organs to transplant, and are, therefore, unwilling to become donors. Psychologists are working to change this fear but agree that the low numbers of registered donors might be more an effect of low motivation to donate, which could indicate the problem may not be as simple as education and awareness of the need to donate organs (Novotney, 2011).

Once researchers can determine why African Americans are reluctant to donate, it may be possible that the adverse effects can be overcome and begin to increase the number of African-American donors, resulting in more lives saved. To make a significant increase in numbers, clergy, social workers, and community educators must become involved in the education of organ donation and work to demystify the organ donation process. According to Reitz and Callender (1993), two issues that surfaced in the examination of African Americans and the process of organ donations are the lack of awareness regarding kidney transplantation, as well as the lack of African American kidney coordinators, who are the individuals who work with potential donors and have the responsibility of educating the public about the need for donors. Furthermore, Reitz and Callender confirmed that African Americans have not always been

willing to donate and that reaching out to the schools, churches, and social workers could provide a new avenue in getting the word out to the African American community to increase organ donations.

Altruism

King (1995) posits that a person needs to decide if he or she will walk in the light of altruism or selfishness. Altruism, as defined by Batson (2011), is an aspirational state with the fundamental purpose of putting another person's well-being or interests in the forefront. Batson's work framed the research on altruism and was founded on an empathy-altruism hypothesis that posits empathetic concern as a motive for helping another. Altruism is the act of putting others before oneself even if it is to one's demise. One would need to perceive or be aware of the needs of another person, and this could produce empathy, which is the precursor to altruism. However, a general concern for the person's well-being must also be factored in.

Batson (2011) asserted that his empathy-altruism hypothesis includes psychological events and consequences to be considered, such as the fact that empathy is not always present when one is in need and that circumstances are also relevant when it comes to the development of empathy. Moreover, Batson asserted that the psychological outcome of altruistic motives deserved some attention. Batson indicated that not all altruistic decisions were for the benefit of the receiver. Furthermore, in Batson's empathy-altruism hypothesis, it is indicated that empathic concern can generate altruistic motivation with no explanation or reason as to why. However, when the motivational precursor is identified, often the reason for the altruistic act is revealed. Empathy-related motives could be generated by the desire to help, get someone else to help, or to take no action at all.

According to Hoffmann (2011), organ donation is listed as one of the most altruistic acts possible. Hoffmann indicated that the only true altruistic donor is a best friend. When it comes to living donors, transplants have more commonly taken place among family members, although altruistic anonymous donors and friends are beginning to step up at a greater rate. Conversely, the motivation of a living donor to donate an organ can be tainted based on the type of relationship with the recipient and the family, indicating potential family pressure or persuasion as a cause of discrepancies in the informed consent process. Alternatively, friends having a close relationship with the person in need may not have the familial pressures to deal with if they decide to be an altruistic donor. With thousands of people on the organ donation waiting list with only a limited number of available organs, altruistic donors are becoming more prevalent. Hoffmann (2011) reported that although altruistic donors reportedly indicated a concern for the beneficiary's quality of life, some had donated as a way of increasing their pride or sense of worthiness. In addition, it was noted that some individuals had anonymously donated organs and then later bragged about their donations.

An organ donor boasting about the donation would reinforce the seminal studies that reported egotistical behavior resulting in self-benefits as being a primary motivator, before the development of the theory of empathy-altruism hypotheses. The act of altruism ends up fulfilling a need for the donor, which is not based on altruism but rather is egotistically motivated for the donor's benefit (Batson et al., 1981). Furthermore, how one feels about any altruistic activity, including factoring in the family's attitude, can affect whether any gift is made, ranging from donating to the local school, donating to the church, or donating an organ.

Living strangers are an untapped resource for altruistic kidney donations as noted by Spital (2001). However, not all donation centers are willing to perform altruistic stranger donations for fear of donors motivated by a reward or mental health issues. Conversations on this resource need to continue to take place and include the general public, as well as physicians, as the study's findings indicate that people are often willing to donate to not only family members and friends, but also strangers (Spital, 2001). In contrast, Batson's (2011) definition of altruism differs from Rachlin's (2002) definition, which is that altruism is a behavior related to genes, which can be passed down from generation to generation; it is who we are, it is in our genes, just like eyesight, eye color, and one's height. Also, he explained that altruism is a motive about behavior; for example, the satisfaction of leaving a tip on the table at a restaurant can be either altruistic in itself or the manifestation of an internal altruistic mechanism of behavior.

The question of why humans behave in a certain way or will even risk their safety to help a family member can be attributed to self-interest (Gintis, Henrich, Bowles, Boyd, & Fehr, 2008). Hamilton (1963) examined blood relatives' high levels of willingness to make sacrifices for each other, while being less likely to do the same for someone they do not know, and "that a predominant quality to be expected in a successful gene is ruthless selfishness. This gene selfishness will usually give rise to selfishness in individual behavior" (Dawkins, 1989, p. 2). Regardless of whether the cause is selfishness or the dominant gene, Batson et al. (1981) indicated that the feeling of empathy could induce true altruism.

Organ Donation Attitudes

Fishbein and Ajzen (1975) contended that there might be a correlation between attitudes and behavior that could be explained by the influence of one specific event and that a person's

attitude regarding a behavior could help predict whether the action or behavior would ultimately be performed. Furthermore, Fishbein and Ajzen (1975) affirmed that people are always aware of the social norms around a given action and that individuals are concerned with how others perceive them; therefore, the norms of how one is expected to behave and these behavior predictions manifest to determine behavioral intentions. Ajzen (1991) and Ajzen and Fishbein (1980, 2005) acknowledged that attitude is a personal disposition, without consideration of the attitude affecting the behavior. Attitude would be the positive or negative feelings toward a situation based on what one knew or believed (Ajzen, 1991). The positive or negative view of behavior, in combination with attitude and feelings, provides a perspective of intention; however, intention does not always predict behavior (Ajzen, 1991). Long et al. (2012) used the research on TRA, and in the study, twenty families participated in a self-conducted interview that gathered information through a series of eight questions. The findings indicated that a positive message about organ donations is needed to increase the number of African American donors. One specific method of change recommended in the study focused on how messages were displayed in the media. In addition, providing education that emphasized the need for organ donors could possibly increase the number of organ donors. The researchers indicated that further information was needed on how African Americans communicated their intention to become organ donors with their families.

In alignment with other research, Morgan (2004) reiterated the relationship between the willingness to donate and the family's discussions, by listing a series of studies that reveal a correlation had been established. Consequently, supporting Fishbein and Ajzen (1975), Morgan, Miller, and Arasaratnam (2002) confirmed that when an organ donation card is signed, the donor

individual has more than likely had the conversation with his or her family. In several studies, Morgan et al. (2003) used the frameworks of donation procedural knowledge, attitudes, and social norms to develop a theoretical model of willingness to donate organs as well as individuals' willingness to communicate their intentions to the family (Morgan & Miller, 2002; Morgan et al., 2002, 2003). Russell et al. (2011) explored the relationship between the intent to become an organ donor and the donor's trust or mistrust of the health care system in a quantitative study. Five hundred and eighty-five ($N = 585$) people were surveyed with significant findings, indicating distrust of the health care system regarding the donation intention. The researchers also revealed that additional study is needed to determine how "distrust in the health care system impacts different types of organ donation intentions" (p. 8). The researchers suggested that the medical abuse present in the Tuskegee Institute Syphilis Study, among other forms of abuse in the medical field, may contribute to African Americans not even seeking medical treatment. Additionally, an inventory tool was used to measure mistrust and indicated that African Americans with high levels of distrust for Whites were unwilling to donate organs. However, the study indicates that results are much more far-reaching, in that the level of mistrust is not limited to just the medical field.

Long et al. (2012) researched the timing of when, and how, individuals discussed their desire to become organ donors with family members and implied that more research would be needed to specify how to impact documented intentions for becoming an organ donor effectively. Also, the researchers examined how the media affects decision-making regarding African Americans becoming organ donors and the decision to discuss the matter with family members but implied that additional research on cultural specific campaigns needs to be considered.

However, based on the Bowen systems family theory of human behavior, which considers the family an emotional unit that truly affects how people think, passing down beliefs and values for generations, the way African Americans communicate could also influence decision-making (Kerr, 2000).

Morgan (2004) also investigated communication among family members and its impact on the willingness to donate organs. Morgan et al.'s (2003) study further supported this research by providing information about identifying barriers in registering to become an organ donor, family consent, and problems registering. Some of the information from this study can help to identify and understand how African Americans discuss organ donations with family members and if discussions help or hinder the decision to become a donor (Morgan, 2004).

“Factors Influencing Organ Donation Decisions by African Americans” is a qualitative literature review conducted by Richard, Darcell, Terry, and Alexander (2007) to identify obstacles and improve new studies and interventions. The authors found that due to the low numbers of African Americans donating organs, a broader exploratory approach is needed to determine barriers despite the current education programs that exist. Future studies are needed to determine the influences of social norms, attitudes, and roles of those directly and indirectly involved in organ procurement and should utilize a research method that will allow for a complete range of predictor variables and actual donation behaviors of individuals and families.

The Experience of Donating an Organ

Meyer et al. (2017) conducted a qualitative, explorative in-depth interview study on the long-term experiences of living kidney donors and found that the experience was favorable for many. The study was conducted to evaluate the donors' lives after the donation. The researchers

interviewed 16 live kidney donors in Norway that had donated between 2001 and 2004. The researchers asked about their experiences following the procedure, including family experiences, any family changes or tension, and if the donor was still healthy. Positive responses were received, such as the donors were proud to have donated and to have saved another's life. Alternatively, a few participants had medical complications and reduced health as well as changed family relationships. Future studies will need to include the resiliency and long-term effects of donors. Also, while the findings indicated a generally positive outcome for those who donated to a family member and had support, the long-term effects of live kidney donations are still mostly unknown. Results indicated that the experience of donating became meaningful because the recipient had a chance at life, while one participant reported that he feels anxiety when the recipient of his kidney goes to the doctor and wonders if the kidney he donated is still working well for his family member. Other donors reported losing contact with the recipients of their donated organ and even received pushback from family members regarding their decision to donate. Some families experience chaos after a member has donated to someone within the family based on feelings of betrayal and the feeling that other family members were not stepping forward to be tested for a match (Meyer, Bjørk, Wahl, Lennerling & Andersen, (2017).

Marck et al. (2016) examined the experiences of the whole family to see the residual effects of organ donations by loved ones after death. The study included 49 participants who were asked questions regarding communication, donation processes, and personal experiences. Communication of death was indicated as satisfactory. The families wanted honest and transparent information regarding the process. In addition, families mainly reported that knowing that another was saved out of their loss was comforting. Supplementary reports revealed that the

process was extensive and stressful; however, knowing someone would live outweighed the level of discomfort for the family. Some families regretted the decision to donate, claiming they wanted to ask more questions about the donation process and have an additional follow-up.

In a study designed to investigate liver donors, Gavin, Malpas, and Bartlett (2015) questioned 45 participants from a New Zealand living liver donation pool. Half of the recipients of the questionnaire identified themselves as being relatives of the recipients. The findings indicated that most of the questionnaires that were returned indicated the donors were satisfied with the results and felt that most people should become donors if they can. In addition, 80% of the respondents were unsatisfied with a New Zealand policy, which allows family members to veto a family member's wishes to donate organs. Furthermore, several participants indicated that education was essential in getting others to donate organs. The researchers reported that fully 100% of the donors were satisfied with their decision to donate, despite a few still having ongoing health concerns given that the surgery is so invasive. This study provided a personal view of the organ donation experience as having positive outcomes and further enhances the current research through its statistical reports and personal viewpoints, touching again on the motivation of being able to save another's life, with some donors even stating they would donate an organ again.

In addition to Gavin et al. (2015), Nasr and Rehm (2014) investigated the experiences of liver donors. Other than these studies, few studies have been conducted on the effects of live liver donations on the parents', families, and child's emotional status. Thirteen participants who were liver donors participated in the interviews. Thematic analysis was used to analyze the data, revealing three categories, which were awareness of self, a better understanding of the family

relationship, and a change in the donor's view of the community. Nasr and Rehm (2014) reported that the donor's family felt the consent process was essential to how the organ donation process concluded. The consent process also contributed to how the family was able to accept the situation, as families often reported being surprised by a request to donate their loved one's organs and were overwhelmed, but able to cope a little better when they had prior knowledge of their loved one's wishes. The researchers examined situations in which, following a loved one's death in the hospital, it was revealed that the loved one had plans for organ donation. The family followed through on the loved one's requests, but often received no further communication of the process. The lack of communication between hospital staff and the lack of knowledge of the process caused additional family stress. However, some families reported the process of donating the organs as being good, because the hospital kept the loved one on support machines for hours or days, giving the family additional time to be with him or her.

Adams-Leander (2011) examined African American living kidney donors. Qualitative interpretive research was conducted to improve an understanding of living donation to genetically or emotionally related recipients. The focus of the study was to provide information about the positive and negatives aspects of the live kidney donors' experience. A significant issue that the researcher identified was the donor's financial burden, resulting from taking off work to complete the donation process and to heal. In this study of eight participants, two people lost their jobs as a result of their donations. Donors also provided information about the interplay between donating and their spiritual and religious beliefs, such as feeling that God had something to do with them being donors. One donor reported that she felt as if the doctor discounted her religious belief by telling her not to pray that her kidney would rejuvenate itself

nor for another kidney because that would not happen. Another issue that was identified was racism, which one donor encountered while in the hospital. She wondered if, had she been White, the nurse would have cleaned her body more thoroughly and ensured she was healthy enough to donate.

Additionally, Adams-Leander (2011) reported that two donors reported encountering attitudes from staff that indicated the procedure was completed so often that it was routine, overlooking the possibility that the donor may be experiencing a new process that could be frightening. Results indicated that more communication would have been appropriate. All participants were concerned with feelings of mistrust as they completed the workup that led to the actual procedure. Three of the living donors who went for a follow-up appointment indicated the doctors and staff appeared not to have time for them. Trust came up in this study when participants stated that the experience either helped them build trust in the medical profession or weakened their current feelings of trust. Participants reported that trust was improved when skilled staff shared information but was destroyed when the procedures and the aftercare were not explained to a level they could thoroughly understand. Some participants mentioned issues such as being informed that there would be two incisions but woke up with three, leaving them wondering if doctors had removed more than the kidney. Also, reports of not being informed of the total healing process prompted emotional confusion at times. Overall, while eight participants had successful surgeries, two later ended up with end-stage renal disease and needed kidneys themselves. This study provided an insight into how the donors felt during the donation process, how relevant communication is during a time like this, and the need for organizations to consider

offering financial assistance to those volunteering to donate organs to release the personal burden of their altruistic gift.

Sieverdes et al. (2018) conducted a study that involved educating family members about the living kidney donor process. The study was based on a video education film to help the person in need of a transplant prepare for asking a family member to be a living donor and donate a kidney. The researchers examined attitudes, concerns, cost, acceptability and increased knowledge in living donor transplants. The video chats lasted eight weeks and were designed to educate and dispel some of the myths of needing both kidneys, religious beliefs, fears, and potential regrets regarding living kidney donations. At the end of the session, participants were more willing to ask a family member to donate an organ, and of the 25 participants, all of them asked at least one person to be a living donor. The results indicated that the video chat sessions provided the knowledge, practice, and assurance to approach family members with confidence to become living organ donors.

Between 1990 and 2005, there were 1,030 kidney transplants, including 800 from cadaver donors and 230 from living donors in South Africa as reported in a study conducted by Abdu et al. (2011). The goal of the study was to explore actual living donors and delve into the family history regarding health and risk. Over the 16 years post-procedure, follow-up was the most crucial task for living donors; however, there were poor reports of follow-up care among the Black Africans in Johannesburg, due to participants' frequent relocation and clinics losing contact. Reasons for donating included having a family member or friend in need, while reasons cited for not becoming a donor included obesity, hypertension, HIV, or other medical issues that would prevent a successful procedure and potentially cause danger to the donor's future health.

Post donation follow-up visits revealed a significant difference in ethnicity; the study showed that fewer Blacks continued the post-donation follow-up care procedures. For those who continued to report for follow-up care, hypertension reported in 24% of the donors' family histories; three donors developed significant damage to the glomerular filtration capacity of the kidney and one developed hypertension. On a positive finding was that none of the donors developed kidney disease in the 16 years of the study. This researcher indicated that since there has been an increase in live kidney donors and the relative newness of the procedure, research needs to continue to study this phenomenon and monitor for long-term risk. This study provided insight into some of the concerns after kidney donations, including health and the importance of continued follow-up care and support for the donor.

Manuel, Solberg, and MacDonald (2010) asked the underlying question of what life was like after agreeing to an organ donation on behalf of a deceased loved one. The researchers examined the themes of needing to accept the death, needing a legacy, extending time, needing a silver lining for the death, and support. The study also helped nurses learn how to overcome some barriers that family members may have with the donation of a loved one's organs. The overall experience with the five themes in consideration was reported as a sense of peace for the family when considering the donation process. The researchers indicated the study could be divided into three sections of importance, including (a) the family experience when donating, (b) the factors influencing the decision, and (c) the experience with the nurses involved with the family and the loved one. In addition, they noted that families who donate might have a difficult time processing the loved one's condition when bombarded with an organ donation request which causes more confusion.

Usually, when a family receives notice of brain death, it is difficult to comprehend because the loved one appears to be still alive and present and the family needs time to process that the loved one will not recover (Manuel et al.2010). Organ donation, while at times has been known to provide a sense of peace through the altruistic donation, has also been known to contribute to a delay in the grieving process for some families. Manuel et al. (2010) reported that when prior knowledge of the loved one's wishes and desire for organ donation were known, the family was better able to proceed with the organ procurement process.

Nurses are an essential part of the organ donor process, as they are often the primary caregiver for the patient and the line of communication for the family; they can both identify potential donors as well as communicate the process to the family therapeutically (Manuel et al., 2010). However, nurses have reported that dual roles have been emotionally and physically stressful. Manuel et al. (2010) relayed the experience of a family to donate organs after receiving information that a relative was brain dead and provided insight into the experience from the family's perspective.

Flodén's and Forsberg's (2009) phenomenographic study of nurses in an Intensive Care Unit (ICU) was designed to elicit information about the nurses' attitude regarding organ procurement. Phenomenography is a research methodology in the interpretivist paradigm that examines the different ways people experience events and how they process the events. Flodén and Forsberg reported that the nurse's attitude was that of "nothing must go wrong," and that the nurses upheld this belief throughout the process. In addition, they reported that different perspectives of the nurses either increased or diminished the chances of transitioning a potential donor into an actual donor. The nurses who carried the attitude of "nothing must go wrong" had

a better outcome of turning potential donors into actual donors. This study reiterates the importance of a positive attitude when working with families, during a time of grief, when they are dealing with the loss of a loved one and are deciding to donate the organs.

Robinson, Borba, Thompson, Perryman, and Arriola (2009) investigated whether African Americans ($N=425$) would donate an organ to a family member, close friend, or stranger. Three quarters of the participants responded they would donate to a family member, and two thirds would donate to extended family or friends. This study indicated broad support for living donors, kidney patients, and their families when considering asking for a donation. Other significant factors in the study indicated that several participants were willing to participate in donations upon death. Surveyed participants were 18 and over and were recruited from various churches in the Atlanta, Georgia area. Findings suggested that African Americans should be informed of what it means to be a living organ donor, learn about the transplant process, and hear stories about the altruistic experience from others that have gone through the process. Hearing firsthand about the experience might help with the decision-making process when a loved one asks for a life-saving gift. Robinson et al. also revealed that one must be aware of the beliefs, knowledge, and attitudes of African Americans before trying to get African Americans that are not on board to provide support. This research contributed to the current research by adding to the information surrounding attitudes and support of living kidney donations, providing an understanding that there is support, and that family members might agree to become a live organ donor to save a relative.

Waterman et al. (2006) conducted a study about the recipients' concerns and educational needs regarding living donations. The results showed that some kidney patients were not excited

about the possibility of receiving living donor organs out of guilt, a possible disappointment if kidney failed, the possibility of living donor needed a kidney later in life, or the possibility of troubling the donor. This study was intended to examine the thought processes of recipients to educate and increase donor participants. The researchers concluded that little is known about the recipients' psychological barriers and educational needs surrounding the organ donor process and that additional education and a thorough understanding would benefit both the recipient and family. This was a focus group, conversational qualitative study completed with 26 recipients, four donors, and three family members that relied on group interactions and discussions, which focused on being on dialysis, deceased donor transplantation, concerns about receiving an organ from a living donor, and discomfort in asking for the altruistic gift. Patients described a benefit of dialysis as being a social gathering to meet friends. Others reported benefits including group support for dealing with the disease. This study shed light on the feelings and thought processes of dialysis patients about accepting a kidney from a living donor, their view of the benefits of being on dialysis, and their feelings towards accepting a living donation. With this perspective, the study provides a firsthand view of dialysis and live donations.

There exists an interplay between organ donation and religion. However, Dixon and Abbey (2003) researched an area known as altruistic religion, and the findings indicate that the medical field has a difficult time handling this approach. In one case, a 46-year-old man called an organ donation center and wanted to become a living kidney donor for a member of his church. The altruistic penitential donation was viewed as a way for the man to relieve guilt for his angry outbursts throughout his life. As the man proceeded through the organ donation process, including psychological testing, it was revealed that he had suffered abuse and self-harm

as a child. However, the individual had become involved in the Roman Catholic Church later in life and identified the religion as influencing his decision to become a donor. The medical profession was reported to have viewed this as an act of altruism that came from an unhealthy motive and believed that additional psychological assessments were needed. The researchers reported that the potential donor's history of abuse, self-harm, anger management issues, guilt, and delusional religious beliefs would not make him a good candidate for the process. This study provided another view of altruism and provides an example of how self-serving endeavors can be labeled as altruistic acts. Furthermore, had this person been allowed to donate an organ, several ethical issues could have been involved, including that the potential donor may have had deep-rooted psychological issues prompting his desire to become a living donor despite the risks.

In addition to religion, the issue of ethics is a part of the organ donor arena. Lafaye and Kreis (2013) raised the issue of ethics in their study when examining whether a physician has a right to accept an organ from a healthy being to treat another or to remove organs from a corpse. These issues had not been addressed regarding it being entirely ethical and cannot be fully and deeply addressed in this brief review. However, the study moves the conversation forward and sheds light on the opt-in/opt-out systems practiced in the United States and Europe, where explicit consent (the U.S. opt-in system) or presumed consent (the European opt-out system) are inherent. With the presumed consent system, it is commonly believed to be all right to take the organs of a deceased person. However, in the United States, explicit consent must be received from a family member. Altruism contains an inherent bias that questions a person's sincerity. This study raised several questions of how ethical altruistic acts are concerning organ donations

but can be instrumental in studying altruism and the procurement of organs through a different lens.

Other aspects of organ donation were examined in Sears, Marhefka, Rodrigue, and Campbell's (2000) study. The researchers examined attitudes of organ allocation based on ability to pay, gender, and smoking. The state driver's license office was used to recruit 681 adults who had read essays or articles regarding heart transplants. Participants were asked to rate their personal views of if a person should have a transplant based on ability to pay, gender, and if they smoked or had ever smoked. The results revealed that people who had never smoked received the highest support for receiving a transplant based on post hoc analysis. The results further indicate that public opinion about organ allocation may be based on smoking history, and not so much on the ability to pay or gender. One of the study's limitations was that although it was conducted at a driver's license office, which offered a variety of participants, being in a college town limited the number of minority groups from which to recruit for the study, and as a result, members from these groups were underrepresented. The dependent variable (attitudes) was somewhat representative but not a decision-making contribution. The study is a significant contribution to the body of literature regarding organ donation because it provides insight into public attitudes regarding organ transplantation based on smoking history, and indicates the public may feel that if an individual smoked or had ever smoked, he or she may have been less deserving of an organ than someone who has never smoked. In addition, the study provided a view of attitudes related to organ donation and whether recipients were deserving based on healthy or unhealthy habits.

Overall, the review of literature contains significant information regarding the shortage of organ donors for African Americans and altruistic behaviors. An examination of the literature covered revealed that there is a gap in research focused on African Americans, the disproportionate numbers on the organ donor waiting list, and traditional family values. Furthermore, in each study reviewed, researchers identified additional research that needs to be completed, whether on the African Americans' personal experience, the living donors' experience, and continued medical monitoring after being a living donor, or the experience of altruism. Ethical issues that were highlighted in the literature include donors ending up with more incisions than previously informed they would have and distrust in the medical field as a whole. To move the research forward, two areas that need additional study would be continued medical follow-up and research on African American donors' post-surgery, as well as additional studies that examine how African Americans communicate their desires to become a living organ donor.

Review of Findings From Literature

When examining the theoretical literature, a few themes were reoccurring such as the need for African-Americans to communicate their desires with the family of being an organ donor. Another theme that presented itself was that a child within the family unit who has been differentiated could be the one to step away from the family and become a donor. The Bowen family theory was supportive of these themes.

Regarding organ donations and the disproportionate numbers of African Americans on the waiting list, more work needs to be done regarding the efforts to spread the word of organ donation needs. The statistics and reality show that African Americans have a higher rate of success if the organs are donated by someone of the same race due to the genetic markers

(DHHS, 2016). To make a significant increase in donor numbers, clergy, social workers, and community educators must become involved in the education of organ donation and demystify the organ donation process (Reitz & Callender, 1993). There have been several studies conducted that provide insight into the lack of organ donor registrations, as well as the barriers for African Americans. Researchers should continue to add to the existing studies, answer questions, seek to improve communication to increase organ donations among African Americans, as well as improve the quality of life for those awaiting transplants.

Donors' trust or mistrust of the health care system plays a significant part in the decision to become a donor. Russell et al. (2011) investigated the relationship between an individual's intent to become an organ donor and the donor's trust or mistrust of the healthcare system. Over five hundred people were surveyed with significant results, which indicated distrust of the healthcare system regarding the organ donation process. The researchers suggested that additional research is needed to determine how distrust in the healthcare system impacts different types of organ donation intentions. However, Radecki and Jaccard (1997) and Resnicow et al. (2012) indicated that future research needs to focus on attitudes and intentions toward donations and that research was also needed to understand how to help motivate younger adults, males, and lower-income individuals with lower education levels to register as organ donors. Also, Russell et al. (2011) revealed that distrust in the medical system among African Americans is an area in need of further research.

Several initiatives can be implemented to improve the rate of organ donations among African Americans. An increase in widespread media campaigns is necessary to educate African-Americans about all facets of organ donation (Kappel, Whitlock, Parks-Thomas, Hong, &

Freedman, 1993). Ginossar et al. (2017) provided evidence about how different racial groups may be reluctant to register or sign their donor cards. In this area, the Bowen theory on family dynamics and communication could be utilized to provide a better understanding. Also, Ginossar et al. asserted that to truly understand the different factors that influence various cultures, the impact of religion must be examined. Siegel et al. (2014) indicated that scholars and practitioners continued to be confused by people's overall attitude toward organ donation and donor registration intention. The attitude appeared to favor organ donations, yet the intention to register remained low indicated a disconnect. Donating an organ is an everlasting legacy and shows altruism at its best. For this qualitative research, the Bowen family systems theory has contributed by proving an insight into family dynamics and the methods of communication with the family, in particular, when a conflict is present.

Some dynamics that affect the prevalence of organ donations are the barriers to organ donor registration based on status, race, and biological sex. Quick, LaVoie, Reynolds-Tylus, Bosch, and Morgan (2016) identified barriers, such as bodily integrity, disgust, medical mistrust, and superstition. The researchers revealed the attitude of young adults regarding organ donations and the barriers mentioned above. The results indicated a negative association regarding body integrity, disgust, medical mistrust and superstition, and organ donor registration. Regarding religion, African Americans are deeply rooted in the church and tend to rely on the church for guidance spiritually and emotionally (Avent & Cashwell, 2015).

Although religion plays a part in most people's lives, spirituality is often neglected during the organ donation process. Isaac, Hay, and Lubetkin (2016) conducted a study on spirituality and primary care physicians. They discovered that a significant number of people want their

primary care doctors to ask them about religious beliefs and practices. The study indicates that religious beliefs and spirituality of healthy patients tends to be neglected. However, a doctor's knowledge of the patients religious and spiritual beliefs can be a support in the individual's care. Furthermore, religious and spiritual attitudes can influence decisions regarding attitudes and health. An individual's beliefs, religion, and spiritual practices have been known to influence his or her health, decisions, attitude and choices regarding alcohol and drug use, organ donation choices, and communication regarding wellbeing and health.

Synthesis of Research Findings

Novotney (2011) wrote a feature report that revealed African Americans feared organ donation due to a lack of knowledge related to the process and an underlying belief that doctors would allow them to die to harvest their organs, and therefore, will not become donors. Reitz and Callender (1993) found that African Americans are often unaware of the process of organ donations and the need for transplantations. They reported that there are very few African-American kidney organ donor coordinators who are tasked with the responsibility of educating the public about the need for potential donors. They also concluded that African Americans are less willing to donate organs customarily. Russell et al. (2011), in a randomized pre-post design with a control group, examined the relationship between the intent to become an organ donor and the donor's trust or mistrust of the healthcare system. The study revealed that additional study is needed to determine how "distrust in the health care system impacts different types of organ donation intentions" (p.42).

Long et al. (2012) used a qualitative interpretative phenomenological analysis research design to study the timing and how individuals discussed their desire to become organ donors

with family members. They used an interpretative phenomenological analysis with twenty families; this qualitative empirical study was conducted through interviews based on grounded theory. The findings of the study showed that the media plays a significant role in the way organ donorship viewed among participants. Long et al. reported that the media consistently portrayed a negative view of the organ donation process. Accurate information targeted knowledge-based campaigns, and awareness of the donation process can significantly increase organ donations. Education is key. Long et al. found that there were few studies on family communication and organ donation. The lack of family communication about organ donations could be based on negative concerns of talking about death in the African American community. However, providing knowledge and awareness in the African American community can eliminate some of the myths and fear surrounding organ donations and intern may increase the number of African-Americans willing to become organ donors. Furthermore, this study has contributed to the field of research about organ donation by answering the question and revealing some of the thoughts and conversations African Americans have regarding organ donations, exposed the lack of knowledge, and revealed how some knowledge about organ donations gained from television has affected attitudes, indicating a need for additional studies in this field.

Morgan (2004) examined communication among family members and their impact on the willingness to donate organs in a qualitative study. Some of the information from this study can help to identify and understand how African Americans discuss organ donations with family members and if these discussions help or hinder the decision to become a donor. Richard et al. (2007) reported findings of a literature review and reported that due to the lack of African-Americans donating organs, despite the current education programs that exist, a broader

exploratory approach is needed to determine barriers. The studies were a mix of qualitative, quantitative and reported articles that made up the literature review; however, each consisted of a gap in the research regarding African Americans who have chosen to become organ donors despite their family values.

Critique of Previous Research Methods

The research literature on organ donations and African Americans indicated that there is a great need for African Americans to become organ donors, supported by the current lack of African American organ donors, according to the DHHS (2017) Organ Donor Registry. Existing literature showed a gap in the qualitative research regarding the African Americans experience of becoming a registered organ donor, traditional family values, and the way African Americans communicate their donation intentions. In reviewing the literature, the most significant studies indicated that further research was needed to provide additional insight into the experience of becoming a registered organ donor and why the tremendous need for organ donors exists.

Long et al.'s (2012) study was a phenomenological analysis used to support the importance of family communication when one decides to be an organ donor. The current research illustrates the family conflict that may occur when one has decided to become a registered organ donor. Long et al. provided some insight on how African Americans communicate the decision to become an organ donor to their family members, how they received information about organ donations and knowledge regarding organ donations.

Morgan et al. (2003) used surveys to complete qualitative research that examined and identified barriers in registering to become an organ donor and family consent. Additionally, they examined communication among family members and their impact on the willingness to

donate an organ. The information from this study can help to identify how African Americans discussed organ donations with family members and determined whether the discussions about organ donations with family helped or hindered the decision to become a donor.

“Factors Influencing Organ Donation Decisions by African Americans” was a qualitative literature review conducted by Richard et al. (2007). The authors reviewed a mixture of cross-sectional surveys/interviews, retrospective chart reviews, and quasi-experimental intervention studies. They reported that African Americans have negative attitudes and feelings about organ donation based on a distrust of physicians and the health care system. Furthermore, African-Americans are reported to be concerned with body disfigurement for traditional funeral purposes and are less informed of the organ donation process. Richard et al. found that due to the low number of African Americans donating organs, despite the current education programs that exist, a broader exploratory approach is needed to determine barriers to organ donation. Furthermore, they discovered that African Americans were in support of monetary lump sum payments or health care discounts as incentives for organ donations, which contrasted with the beliefs and attitudes of White participants in the studies that were reviewed.

The current qualitative case study consisted of an examination of the experiences of African Americans becoming a registered organ donor. Morgan (2004) and Long et al. (2012) both revealed communication and family influence as a critical component related to family consent. These are essential attributes of the current research; also issues, such as the families’ fear of healthcare, body disfigurement and lack of knowledge of the organ donor process contributed to this study.

Summary

In conclusion, when considering undertaking any new research, examining the contribution that the study may make to the field is good practice. Furthermore, the problem examined, the types of questions asked, and the philosophical assumptions brought to the study all contribute to the research methods and the scientific method. Although this researcher determined that a qualitative case study design was best for this research, quantitative research method designs continue to hold valid options regarding correlation questions within this study. The literature review revealed a need for additional research regarding family values and African- Americans. The questions allowed for a well-rounded, in-depth insight into a cultural phenomenon that may provide a deeper understanding of the barriers that affect the number of African American registered organ donors.

CHAPTER 3. METHODOLOGY

Purpose of the Study

The purpose of this chapter is to review the methods used to conduct this research study. This case study was conducted to understand the experience of African Americans who have chosen to become registered organ donors despite their traditional family values. A qualitative case study design was followed using Stake's (1995) research model. This researcher conducted one-on-one interviews to gather data; the interviews were transcribed, analyzed, and separated into themes and patterns before being written into the findings.

Research Question

How do African Americans who have chosen to become registered organ donors describe their experience despite traditional family values? The research question fits into a qualitative, explorative arena that focuses on a real-life phenomenon.

Research Design

This qualitative case study was designed using the Stake (1995) model. Stake refers to the case study "as the study of the particularity and complexity of a single case, coming to understand its activity within important circumstance" (p. xi). Yin (2014), another expert in case study methodology defined a case study as an "empirical inquiry that investigates a contemporary phenomenon in depth and within its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident" (p.16). Therefore, a case study should be conducted because one wants a better understanding of the phenomenon or case of interest (Yin, 2014).

Qualitative case study designs generally consist more of exploring questions of how and why something has occurred the use of open-ended and general questions. In qualitative designs, the researcher can become a part of the research in a holistic manner. However, becoming a part of the research can also be viewed as a challenge to the credibility and impartiality of the study. Shortcomings of qualitative designs have included scarce or insufficient information, and the ability to remain detached from the participants and the situation. The qualitative research approach is used when a researcher wants to understand or explore the meaning or social problems of a group. Stake (1995), “two principal uses of the case study are to obtain descriptions and interpretations of others” (p.64). The sources of data for qualitative methods can include focus groups, interviews, or observations, as well as secondary sources, diaries or notes, followed by structured and coded data grouped, themed and analyzed.

Triangulation described by Stake (2010) “various habits” (p. 123) researchers use to get the meanings straight. Triangulation is therefore the process of applying more than one method to collect data. In the current study the researcher used open-ended questions in an interview process with participants as well as field notes to record the participants behaviors, attitudes, voice tone and take note of whether they were excited, inquisitive, serious or angry while explaining their experience. The interviews and the field notes were methods used to collect the data for this study.

Qualitative research can allow a more descriptive interpretation of emotion and personal views (Madrigal & McClain, 2012). From qualitative research, one can learn about the human experience, concerns, social norms, religious beliefs, and attitudes. Researchers who conduct qualitative research can use several methods and procedures to perform the study, ranging from

interviews to focus groups and observations. In qualitative interviews, the questions are open-ended and include who, what, and when of the phenomenon. In qualitative interviews, one must probe appropriately, keeping the interviewee on topic and talking without guiding them into answering questions in a biased way (Patton, 2015). Interviews in case studies are considered one of the most effective forms of data collection (Tellis, 1997). Case studies are ideal methods of research when examining an area of interest consisting of observable behaviors and experiences that can be captured in an interview session (Yin, 2014). Stake (1995) had a more flexible approach to case study research compared to Yin (2014), which can be more appealing to some researchers Yazan (2015). Stake suggests the researcher have a set of two to three well developed main research questions followed by more subsequent questions. However, per the Capella University Psychology Department rules, only one main research question is advised.

Target Population and Sample

The target population for this study was African American participants in the United States, both sexes, over the age of 18, registered organ donors who have experienced some conflict or disagreement with family about becoming a donor and were willing to participate in this study and share their experiences. Stake (1995) does not require a certain number of participants for a case study, though a smaller number allows the researcher to concentrate on the individual cases, giving each case undivided attention and a thorough investigation. This sample size consisted of nine participants, mainly from the southeastern part of the United States.

Population

The recruitment consisted of a nationwide search, which was conducted on the Internet through social networking and research recruitment platforms. The population for this study consisted of

African American women and men living in the United States who have chosen to become organ donors and have experienced some family conflict surrounding their choice. These participants were over the age of 18 and willing to share their experience for the purposes of this research.

Sample

The sample size of both sexes consisted of nine African American participants, living in the United States, and willing to share their experience of becoming an organ donor despite the impediment of traditional family values. Purposeful sampling was used in this case study to provide valuable information regarding the organ donors' experience of becoming an organ donor despite traditional family values and not just a generalization of the experience. The participants were not related to this researcher, and the researcher did not have a personal or working relationship with any participant. Saturation within the study was reached when the events and experiences within them provided adequate information to support the experience without generalizations. According to Stake (1995), keeping generalizations and particularizations in balance is important.

The requirement that the participants had experienced some conflict when becoming a donor is one of the aspects that separates this research from other studies and was deemed necessary for the study. The researcher sought to recruit a balanced number of participants to provide a perspective from both sexes equally and provide an essential balance to the study. In the process of concentrating on the experiences of the African American participants who have chosen to become a registered organ donor despite traditional family values, the research question guided the study. The research question allowed the participants to contemplate on how they felt about the organ donation and to give a detailed interpretation of their experiences, so

that there can be a better understanding of the struggle, the anxieties, and the complication of the decision of becoming an organ donor and being in an African American family that was against their decision (Stake, 1995).

Procedures

The researcher posted/shared the invitation to the case study daily or until the required number of qualified participants had been received. In addition, a single web page was created, where potential case study participants could register if they did not have access to social networking. The secure domain site displayed the same information as the flyer and requested that if an individual was interested in participation, to please contact the researcher. The web page, and social networking postings were removed once the desired number of qualified participants had been reached.

Snowballing was also used, in which someone told others about the study and used social networking to request participants for the study. In addition, there were social networking pages dedicated to helping psychology students recruit participants for research projects where the recruitment flyer was posted. A kidney walk/run was held in a major metropolitan area and flyers were dispersed, which resulted in many potential participants recruited. To find participants, a website was created to allow potential participants to respond with their interest. Other social networking websites were used to find eligible participants.

Participants Selection

A participant's selection was based on meeting the sampling criteria of being African American, both sexes, over the age of 18 years old, having the experience of becoming an organ donor despite traditional family values, and willing to share his or her experiences. Once selected

and screened to meet the criteria, participants were asked the interview questions for data collection. This researcher was careful to qualify only participants with whom this researcher had no prior relationship.

Protection of Participants

Participants' confidentiality was always of concern during this research. Therefore, a secluded area was used for interviews and audio recordings, documents were coded and kept in a secure location to protect anonymity, all e-mails and phone messages were password protected, and participants' identities were kept confidential. After seven years, the records and recordings will be destroyed appropriately. Prior to participants agreeing to be in the study, an informed consent form was signed; participants were given a copy of the consent form, and this researcher kept one. The raw data and the resulting analysis are kept secure on a cd or jump drive in a locked safe for seven years, then destroyed.

This researcher posted to personal social networking pages soliciting volunteers, which included the researcher's contact information. Interested volunteers/participants called or e-mailed the researcher. If e-mailed, the researcher responded with an e-mail request for a phone interview at the participant's convenience. If the volunteer/participants agreed, the researcher obtained an address to mail the consent form and a self-addressed, stamped envelope. If the participants did not agree, the researcher terminated contact with the potential participants, with a simple "thank you for your interest." After the signed consent forms were mailed back to the researcher, the researcher contacted local participants to schedule face-to-face interviews to be conducted in a secluded area. Upon the completion of the interview, the participants received a

\$20.00 visa or shopping card. The participants' names and personally identifiable information were assigned a code.

Data Collection

The data for this research were obtained through the observation of the nine participants from the initial introduction (meeting), and the in-depth interviews with the participants (Stake, 2010). The participants joined in a private, open-ended question and answer session, which lasted about an hour each. The data obtained allowed for an insightful picture of the participants' experiences and a full understanding for this researcher to draw upon in the process of conducting this study. The interviews took place in a private study room at the public library for most participants, and through Skype for a few remotely located participants.

Stake (1995) pointed out that a collection plan of developing and identifying the case, developing questions, having a list of information sources, allotting appropriate time, calculating the costs, and accurately reporting the data make for a more organized process. The types of data used and collected in this research included direct observations (behaviors), during the interviews and open-ended interview questions beliefs/values. Qualitative research interviews play an essential role in data collection and gathering detailed information about the group studied or human experience being investigated (Creswell, 2013). From qualitative research, one can learn about human experience and concerns, social norms and ethnicity, religious beliefs, and attitudes. In qualitative interviews, one must probe appropriately, keeping the interviewee on topic and talking, without guiding the interviewee into answering questions a certain way. The interviews have been audio recorded and transcribed, as the findings in case study research often involve exact quotations (Patton, 2015).

This case study used the following:

- Interviews data (e.g., open-ended conversations with key participants),
- Field note/Direct observations (behaviors) during the interviews (beliefs/values)

reported, as well as documented review analysis through the interview questions asked in the interview. Field notes are the researcher's thoughts and observations during the interviews or about the participant jotted down on paper and are often used by researchers to help recall or record information during the data analysis. Field notes, such as the researcher thoughts and quick observations of the participant were instrumental in recording the participant's reactions and attitude. According to Phillippi and Lauderdale (2017), field notes documenting the observation are advised to help recall the interview during data analysis. Furthermore, as stated by Stake (1995), observations move the researcher toward a deeper and meaningful understanding of the experience. Field notes were used in this study as the researcher observed the participants reactions to the questions, the emotions and tone in their voice, and whether they were serious or inquisitive.

To reach the broadest potential audience in the shortest amount of time, this researcher used social networking and word of mouth, and a single registration web page as the platforms to recruit qualified participants. In the process of reporting the data that have been collected, triangulation was utilized, which is "the convergence of data collected from different sources, to determine the consistency of findings" (Yin, 2014, p. 241). In this case study, data collected from nine different participants and the need to determine the consistency of findings are relevant.

Data Analysis

According to Stake (1995), data analysis can begin at any moment. The analysis is giving meaning to first impressions as well as final accumulations. The following is a systematic description of the procedures that have been taken to complete the research data analysis. Regarding case study data analysis, it is crucial to remain organized to keep from becoming confused during the examination of the well-rounded bounded system (Creswell, 2012; Stake, 1995; Yin, 2015). Data analysis involves several steps, including thoroughly probing, assessment, and organizing the information to write it into a report correctly.

According to Yin (2014), data analysis encompasses examining the data, categorizing, and testing, as well as tabulating and addressing any problems that may arise during the study.

According to Stake (1995), qualitative studies capitalize on making sense of ordinary ways. Staying organized and organizing the data is extremely important throughout each of the following steps:

1. Describe the case.
2. Direct interpretation of the case
3. Categorical aggregation to reach meaning
4. Within-case analysis
5. Across-case analysis
6. Interpretive phase to look at and develop generalizations. (Stake, 1995)

In addition to the above breakdown of analysis, the following steps have been taken:

1. Transcribe the recordings.

2. Read the data transcript and underline any sentences, phrases, or paragraphs that appear to be meaningful; however, no interpretations now. Stake (1995) suggests the use of specific aggregation or direct interpretation for every participant's data set.
3. Search for patterns and look for consistency.
4. Use other cases to generalize, for natural generalizations.
5. Review the underlined data for relevance and decide if the underlined data is related to the research question.
6. Omit all irrelevant information.
7. Name and code remaining information related to the question including expression.
8. Cluster the sets of data (expressions or meaning units) that are related or connected in some way and start to develop patterns, then name each pattern.
9. Using transcripts, write a description of the pattern using quotations.
10. Investigate overarching themes in all patterns (cluster them).
11. Arrange themes in similar theme pattern order.
12. Write a detailed analysis describing the scope and substance of each theme for each participant.
13. Describe and clarify supporting quotes from the data of each pattern. Then the research develops a synthesis of the participant's data combining the patterns and themes to represent a whole of the experience being investigated (within-case analysis).
14. Combine the analysis of data for all participants including patterns and themes that are consistent across the participant's data (cross case analysis).

15. Use member checking to verify the accuracy of quotes and statements of the participant to assure accuracy.

Instruments

This case study consisted of open-ended interview questions to collect data. In this qualitative research, the questions were tailored specifically for this study and allowed the researcher to gain an in-depth view of the experience of the participants. The researcher is allowed to be the instrument in qualitative research. Open-ended questions provide opportunities to ask additional questions, as participants answered and pondered over the responses further information was revealed and considered valuable during the question and answer sessions (Stake, 1995). One purpose of case study research, according to Stake, is to explore a phenomenon within a case, an individual or a group. The use of interviews in a semi-structured informal session allowed for the questions and answers to guide the data and provided more detailed responses than just “yes” or “no.”

The Role of the Researcher

According to Stake (1995), the researcher plays many roles from “participants observer, interviewee, the reader to storyteller, advocate, artist, counselor, evaluator, consultant” and other positions if one so chooses; however, the researcher decides how much importance to put into each role. This researcher chose the role of interviewer, evaluator, and participants’ observer in an effort to analyze and understand the total experience thoroughly. The most critical decision the researcher should make in the study is to be him/herself during the research process. In addition, the researcher should apply qualitative standards of credibility, dependability, and transferability to the processes of monitoring and reducing bias, developing competence in one's

methods, collecting the data, analyzing the data, and presenting the findings in an ethical, unbiased manner (Stake, 1995).

Furthermore, just as the researcher should ensure the data are explained and documented without bias, one must also stay within the appropriate design when documenting and collecting data, making appropriate field observations, thoroughly analyzing the data. Stake (1995) lists the following as the roles of researchers:

- Teacher to inform
- Advocate
- Evaluator
- Biographer
- Interpreter

Qualitative analysis, according to Patton (2015), involves the study, collection, use of interviews, personal and experiences, to describe several realities that explain routine and challenging moments and meanings in life.

Researcher-Designed Guiding Interview Questions

Stake (1995) confirmed that “Qualitative case study seldom proceeds as a survey with the same questions asked for each respondent; rather, each interviewee is expected to have different experiences” (p. 65). The interview should be comfortable and relaxing, almost conversational, with open-ended flowing questions in a continuum forum, both in-depth and naturalistic, in order to gather the best data (Edwards & Holland, 2013). The researcher asks guiding questions and allows for the questions and answers to guide the conversation. According to Stake (1995), “the

best research questions evolve during the study” (p. 33). The following questions have been included as a part of the case study design:

1. Describe the experience you have had talking to your family about your decision to become an organ donor.
2. How has becoming an organ donor impacted your life?
3. What leads you to believe that your family would or would not support your decision to become an organ donor?
4. How do you feel about your family’s values regarding organ donations?
5. What specific resources did you find to be helpful in your decision that you might share with family members?
6. Can you describe what made you decide to become an organ donor?
7. Can you describe the experience of the moment you decided to become an organ donor?
8. Are there any questions you can think of that I did not ask, or is there any additional information about your experience that you would like me to know?

Ethical Considerations

Yin (2014) points out “that a good case study researcher, like any other social scientist, will strive for the highest ethical standards while doing research” (p.76). Avoiding bias and protecting the confidentiality of participants are only two aspects of ethical considerations in research. Plagiarism, falsifying information and being honest and responsible all play a role in maintaining ethical fidelity in research. However, as stated previously, confidentiality is an ethical concern in any research. Therefore, the public library was used for interviews, the audio

recordings and documents will be stored on a disk drive, well maintained and locked in a safe and stored in a secure location for seven years, all email and phone messages are password protected, participants' identities are kept confidential, and any records and data destroyed after seven years will be securely shredded. Prior to the participants being included in the study, an informed consent form regarding their risks and rights during the research process was explained and signed. The participants received and signed a consent notice regarding publication (Percy, Kostere, & Kostere, 2015). This study was not considered to contain extremely sensitive data based on the IRB Risk Assessment, which further stated that no interventions are needed, as the study presented a minimal risk. The documents, the audio recordings and all data are locked in a safe in a secure location. All data will be securely shredded and or burned after seven years to maintain protection and secure identity.

Summary

The sources of data for qualitative methods can include focus groups, interviews, or observations, as well as secondary sources like diaries or notes, followed by the structuring and coding of data into groups and themes for analysis. However, this researcher focused on interviews with open-ended questions, and observations. Qualitative research can allow a more detailed interpretation of emotion and personal view (Madrigal & McClain, 2012). This research could have been completed with a quantitative methodology; however, it would not have supplied such an in-depth breadth of knowledge of this cultural phenomenon, and therefore, would leave questions unanswered. The barriers regarding African Americans and family values are believed to run deeper than merely determining a relationship between the two variables, and therefore, a profound understanding of the obstacles is needed and can be captured through in-

depth questions and answers. Chapter 4 will discuss the data in depth and describe the within-case analysis as well as the cross-case analysis, list a description of the participant sample, and present results of the data analysis.

CHAPTER 4. PRESENTATION OF THE DATA

This chapter contains details of the data analysis conducted to answer the research question: “How do African Americans who have chosen to become registered organ donors despite traditional family values describe their experience?” The study is a qualitative multiple-case study, which used Stake’s (1995) model of case study research. The sample consisted of nine African Americans who met the research eligibility requirements and were willing to participate in the study. The data were analyzed using both within-case analysis and cross-case analysis processes. The within-case analysis consisted of finding patterns within each case, and the cross-case analysis involved examining the data from all participants collectively.

The Study and the Researcher

This researcher wanted to learn more about the experiences of African Americans choosing to become registered organ donors against their family’s wishes because of experiencing a family member’s journey through kidney disease and the long organ donor waiting list. The experience triggered a desire to understand the phenomenon better, and that desire prompted this research. The researcher enrolled in the Capella University PhD program in general psychology to develop an understanding of African Americans’ experience when becoming a registered organ donor. Extensive course work and literature reviews aided in the development of a thorough appreciation and comprehension of the topic of organ donation and the studies that have been conducted previously. During the required coursework, the researcher learned to conduct qualitative research through courses such as Research Methods and Research in Psychology. Data analysis techniques were acquired through the Qualitative Analysis and the Advanced Qualitative Analysis courses. Ethical considerations are of the utmost importance in

qualitative research. As a result, this researcher enrolled in the Ethics and Multicultural Issues course. These courses were instrumental during the research process. Also, while a scholar at Capella University, this researcher read and became very familiar with the works of Creswell (2012), Merriam (2009), Stake (1995), and Yin (2015). In the present study, Stake's (1995) *The Art of Case Study Research* was embraced, and the data collection and research design model were followed and presented.

Description of the Sample

A total of nine individuals participated in this study. Participants self-identified as African- Americans who had experienced some conflict or disagreement with family members about their decision to become a registered organ donor. All individuals took part in the study willingly and shared their experiences voluntarily. Participants were recruited from various social networking sites, and most lived in the southeastern part of the United States. The study consisted of participants from both sexes willing to share their experience for the purposes of this research. The participants' ages ranged from 40 to 67 years old with an average age of 50. All nine of the participants were willing to remain a part of the study through completion, and no one dropped out of the research. Eight of the nine participants were contacted for member checking and confirmed that the interviews had been transcribed verbatim as far as they could remember. Member checking provides a way to ensure and verify accurate transcribed data obtained and transcribed to depict the participants experience. Member checking provides the participants an opportunity to confirm or deny the accuracy of the transcribed data, which adds to validity. One participant did not respond to the phone message or e-mail sent by this researcher regarding the opportunity to review the transcripts. To ensure that participants' identities remained

confidential, identifiers were used designating members of the sample as Participants P1-9. The identities of the participants are known only to the researcher. Table 1 contains a description of the sample, including information on each participant’s age, marital status, employment status, and education.

Table 1. *Description of the Sample*

Name	Age	Married	Employed	Education
P1	54	No	Yes	College Graduate
P2	47	Yes	Yes	Graduate Degree
P3	47	Yes	Yes	College Graduate
P4	42	No	Yes	Graduate Degree
P5	40	No	Yes	College Graduate
P6	67	No	Retired	College Graduate
P7	49	No	Yes	College Graduate
P8	51	No	Yes	College Graduate
P9	56	No	Yes	Associate Degree

As indicated in Table 1, the sample contained a range of participants between the ages of 40 and 67. The average age of the participants was 50 years old. Most of the participants were not married, and all but one of the participants were working at the time of the study. All of the participants had participated in some level of postsecondary education, with participants holding associate’s, bachelor’s, and graduate degrees.

Research Methodology Applied to the Data Analysis

Stake’s (1995) multiple-case study research and methodology were utilized in this study. Triangulation in qualitative case studies entails the use of multiple sources of data to maintain validity. Using multiple sources of data to understand the experience can be valuable in the research (3 Triangulation of Data Sources, 2018). According to Stake, a “qualitative study capitalizes on ordinary ways of getting acquainted with things. Things get recorded” (p.49). The primary form of data collection consisted of interviews where participants were asked open-

ended questions. The answers were recorded on a voice recording device, and the researcher took notes regarding participants' expressions, moods, and attitudes. Some of the notes described the participants' attitudes and tone (participant's attitude towards the issue). Stake noted that during data collection, researchers are tasked with noting points they feel are worthy of consideration and drawing conclusions that were meaningful to other researchers. This researcher considered the participants' attitudes during the interview and made notes if the participants appeared to be excited, emotional, or withdrawn during the interview process. Participant 1 was inquisitive and appeared excited and interested in the research with a quest for more information. Participant 6 was serious yet engaged; her tone was straight forward with an attitude and desire of getting things done. She wanted to spread the word to the clergy in an effort to get more African Americans involved in registering to become organ donors. Participant 9 was stern and straight to the point. He had a very serious attitude, and his tone was straight forward as noted during the interviews and observations. No other data regarding attitudes from the participants was significant enough to add.

Stake (1995) suggested using a data-gathering plan rooted in the research question that consists of the case definition, a list of research questions, identified helpers, identified data sources, a list of tracked time and cost, and a description of how the data were to be reported. Each participant was sent the definition of the study and the research questions before the meeting. On the day of the interview, the participants received another copy of the questions to review prior to the start of the interview. The use of a transcription software was part of the original data-gathering plan; however, this portion of the plan was abandoned due to delays in

the transcription software process that began to interfere with the interview process and a transcriptionist was secured.

Time allocated for the data collection portion of the study began after the receipt of IRB approval and continued through the completion of the data analysis and the acknowledgment that data saturation had been reached. Member checking was used to confirm the accuracy of the interview transcripts and the validity of the findings. Within-case analysis was used to determine patterns associated with each participant's experiences, and across-case analysis identified themes based on patterns observed in the experiences of all the study's participants. The data analysis process consisted of the following seven steps:

1. Once complete, the researcher listened to the recorded interviews.
2. The researcher transcribed the interviews and then compared the transcriptions to the recordings.
3. The researcher highlighted important sentences within the transcribed interviews in an effort to identify meaningful passages.
4. The researcher reviewed the highlighted passages to ensure the participant was answering the question. Irrelevant information was set aside.
5. A within-case analysis was then conducted for each participant, and similar meanings were grouped together to determine patterns.
6. A cross-case analysis was then conducted using the patterns to form themes.
7. The themes were then used to answer the research questions.

Presentation of Data and Results of the Analysis

The presentation of the data is divided into two parts: the within-case analysis and the cross-case analysis. The following results reveal the patterns and themes that emerged from the data once the researcher completed the data analysis of the nine participants. The researcher spent several months going over the data, reading, highlighting, verifying the findings through member checking. The within-case analysis focused on the meanings and patterns within each case, and the cross-case analysis allowed overall themes to emerge from the data.

Within Case Data Analysis

The first step in the data analysis process was to conduct the within-case analysis for each participant. Participants' statements were grouped to discover and accurately report the meanings and patterns that emerged during the interviews of each of the nine participants. These meanings were then grouped to identify patterns in the data. The patterns that emerged for each participant are described in the following subsections.

Participant 1 P1. Four patterns emerged for P1. During the data analysis, the patterns were: (a) negativity, (b) refraining from further discussion, (c) basic goodness, and (d) community outreach. The patterns are described separately in the following subsections.

Pattern 1a: Negativity. The first pattern that emerged for P1 was a pattern of negativity. P1 described the experience of becoming a registered organ donor despite traditional family values, as negative, especially with regard to her mother's reaction. The conversation about P1 registering to become an organ donor took place over 20 years ago, and although no recent conversations have taken place, P1's mother is now on kidney dialysis and in need of a kidney donor herself. P1 noted that as a result of this change in circumstance, the conversation about

organ donation may have been more positive if it had been held today rather than over 20 years ago. P1 offered the following three statements related to Pattern 1a:

“The experience initially was quite negative. Basically, why would you want to do that? You don’t know who might get your organs. You should leave with what you were given when you came here. Just very negative. That was initially.”

“She was just not receptive to the idea at all.”

Yeah, just negative. Now if I were to have that discussion with her now because of what she’s dealing with, it may be different, but I have not. Initially, through her situation, she was not receptive to having the organ from someone who was deceased, and I didn’t understand what difference does it make if it were a viable organ.

Pattern 1b: Refraining from further discussion. P1 described the experience of becoming a registered organ donor despite traditional family values, as refrained from discussing organ donation with the rest of her family. It had been over 20 years since the first conversation about organ donation took place with her mother, and she has not informed any other family members of her decision. P1 has adult children and a brother that she now feels should know about her decision. Because P1 had a family member die of kidney failure and her mother now needs a kidney transplant, she wants to inform her family that she is a registered donor in the event something was to happen to her. P1 offered the following responses to questions about her family’s discussion of organ donation.

We’ve not had a discussion about my participation as a donor, but I have attended some of the appointments with her, and she was interested in having a live donor, which I thought was really ironic because of the discussion before I decided to become an organ donor.

“I have not had a discussion. I only have one brother, who’s younger, and he has four children, two grands. We’ve really not discussed it because he wouldn’t be a part of the discussion necessarily.”

“She has eight sisters and brothers. Maybe she thought they would be a better match and would come on board, but she’s not even had the discussion with them.”

My son is 26, and like I said, we’ve not had a discussion, but he would wholeheartedly support it. Right, and that’s why I had the discussion, and when I leave here, I’m going to call my son because I don’t know that I even told him. You know, if something happens to me, I’m an organ donor.

Pattern 1c: Basic goodness. P1 described the experience of becoming a registered organ donor despite traditional family values, as an act of basic goodness, the ability to help someone, and a decision that could change or save someone’s life. P1 explained that if the organs are in good shape after someone is deceased, then they should be used to save a life. P1 very strongly questioned the meaning of not donating them, and at one point, she asked, “Why take them with me?” P1 noted that the organ donation process can prolong other people’s existence on this earth. P1 also mentioned that the ability to help others survive with an organ that is no longer needed could be a way of living on through that person or simply just being able to provide an extension of life. P1 offered the following responses related to the inherent value in organ donation during the interview process:

Well, I guess I’ve always thought, well why destroy something that can be used to help someone else? This, my decision to become an organ donor came way before my mother’s situation. I think I was maybe in my late 20s. It was time to renew my license, and of course, the question is, you know, “Would you like to be an organ donor?” And I’m like, yes. I never even thought about it. It wasn’t like a painstaking decision of any kind. It was just the goodness of me, I guess. I don’t know how else to describe it, but I never even gave it a second thought.

Well, why take them with me? If they’re, like I said, viable or useful to anyone, then I’d rather they go to someone that can use them. Save a life. Rather than just be, I don’t want to be morbid, just taken out and thrown away basically. So, I’d rather someone that could use anything, any organ.

“So, I think I was thinking, well this would be a decision that would change or save someone’s life.”

Pattern 1d: Community outreach. P1 described the experience of becoming a registered organ donor despite traditional family values, as community outreach. P1 further described her desire to educate the community and get the word out about the importance of organ donation. P1 stated that the community needs to be aware of the need for more registered organ donors. P1 suggested that increasing awareness through churches, recreation centers, and the department of motor vehicles has not been enough. P1 specifically questioned the lack of organ donation among young people. P1 noted that providing knowledge through community outreach could help inform people of the shortage of organs and the need for more registered donors. P1 suggested that providing information on how organ donors save the lives of individuals on the waiting list would help, especially if it became clear that individuals on the transplant list often die without a transplant. The following statement from P1 contributed to the pattern of community outreach.

“I don’t know how you reach our community to not necessarily educate them but know the importance. I mean, with the news of today all these young kids are dying.”

“It’s just, how do you educate our community of the importance of organ donation when...especially because it’s so violent.”

“I don’t know how you could get the word out.”

Participant 2 P2. The second within-case analysis involved P2. Five patterns emerged during the interview with P2, which were: (a) family being really shocked, (b) communication is necessary, (c) selflessness, (d) knowledge resources, and (e) lack of trust.

Pattern 2a: Family being really shocked. P2 described the experience of becoming a registered organ donor despite traditional family values, as family being really shocked when he

informed them that he had become a registered organ donor. Being shocked, stunned, and surprised created several questions. P2's family wanted to know how he could be willing to give significant parts of his body away. P2 realized during his first conversation with his family about organ donation that when discussing being a registered organ donor, one must think about and be able to discuss death and dying. P2 felt that this was sometimes difficult because many people do not want to face the inevitable, but P2 clearly felt these conversations were necessary. P2 offered the following statements related to Pattern 2a:

“I said it out loud before I went to get my driver's license that I was going to make sure I put on there that I would be an organ donor, and it was like I had cursed them out or I had done something just to draw some really negative attention to the family. They were like they couldn't believe.”

There were a lot of questions about why. Why would you want to do that? And it didn't stem from, I don't think, a religious kind of anything or why would you defile your body; it's they couldn't understand why I felt that I could give parts of me to other people, like significant parts of me. I said, but I won't need them.

Initially, they just outright said it that they would not. They didn't support it. So I didn't have the confidence that they would do it if I couldn't say something, so I made sure that I had it both on my driver's license so that I initially when I was in South Carolina I did have an additional card that I carried with me to make sure, but I told more than one person. I told multiple people in and outside of the family so that it would become common knowledge.

Pattern 2b: Communication is necessary. P2 described the experience of becoming a registered organ donor despite traditional family values, as making sure it is a part of the discussion with the family, so that they are aware of his organ donor status. P2 talked about a family member who passed and wanted his organs donated; however other family members did not agree and therefore split the family and created disagreements. The organs were not donated. The family has the last word on one's body upon death. Therefore, communicating one's wishes

should be considered thoroughly. P2 thought it was essential to discuss with all of his family members, as well as adding it to his end of life wishes, so that everyone would know his wishes and there would be no doubt.

Yes, we had talked about it before, but just bringing it back up, he just kind of reaffirmed what he had said before in that he knew I was an organ donor. I said that my wishes were to have my organs donated if that was an option, and he just clarified that, yes, he would definitely make sure that happened.

And the discussion, just the discussion in general. I don't think, I mean people don't talk about it. People don't ever say anything about it. You know, before our conversation about it, the last time I think I really ever had a conversation about it was with my friend was doing that job. It was his job to, to meet with families and breach that, you know that, try to, try to breach that void I guess and just bringing up the subject.

“This doesn't happen enough. Since we all think we're going to live forever, we don't have to think about those things or consider those things. But it's worth the conversation.”

I mean, that should be the goal. It should be. Just having the conversation will make more people aware that it is needed. I mean, a lot of people think about organ donations and they think of, “My sister or my brother needs a kidney. Should I go get tested?” That's probably as far as they think about it and don't think anymore.

Pattern 2c: Selfless. P2 described the experience of becoming a registered organ donor despite traditional family values, just being willing to give of oneself and donate a body part can be considered generous. P2 has a desire to give back to society or to be of use to others beyond his earthly existence. Donating one's organs can be a way of leaving a legacy, as a part of you lives on in another being. To be generous and altruistic in death, while helping to save a life, could be the ultimate description of a selfless act.

“It is pointless to be cremated with them if they're good or buried with them if someone else can use them. Why would I? That's just kind of selfish to me.”

“Well, I think I didn’t have a lot of things that I felt like I could give society at the time or be potentially be a help to anybody else, and that was the one thing that was completely under my control. I got to make that decision.”

Plus, my thought process is always like “Ok if I can’t use it, why do I need it? What’s the point of keeping it?” I mean, again, it’s like ok, the ultimate idea of being selfish, I guess, is to take things with you to a place that you can’t use them, at a point where you cannot use them anymore, to keep them or to have people say, “No, I’m not going to help other people.”

I just think that not, and from my religious background too, I just think that it kind of flies in the face of the big Christian point of view, being able to help one another and sacrifice for yourself to help somebody else, and I don’t think it’s really a sacrifice because you can’t use them anymore at that point.

Pattern 2d: Knowledge resources. P2 described the experience of becoming a registered organ donor despite traditional family values, as having knowledge and resources to explain the process and possibly change minds regarding being a registered organ donor. When people know someone in the medical field or they have resources to share with their family about the organ donation process, it makes it a little softer to convince the family and friends to accept the decision of being a registered organ donor. The more information and examples of lives being saved can be a point of influence for the family.

It was good that I had a good friend in college that was in the medical field. Well he still is; he’s a nurse. So, he was going to school with me at the same time, but he also worked as the liaison between the hospital system and potential organ donors. He was able to kind of be at the house with my parents one day and explain exactly what his job was and what they need was. So, he had specific examples of people in need. He had numbers to say how often it was needed and what kind of shortage there was.

You see it on TV; they read a lot of articles about it. I think it was a combination. Those were the biggest things; having somebody that they knew already being in the field, working in that area and being able to explain and being able to kind of one-on-one answer their questions if they had any.

I think that kind of thing. I think not just talking about it but being able to show the end result and how it affects people would change minds or at least open minds up to the consideration. When you see a living breathing person in front of you, or at least at a minimum on TV, and you see their reaction, their feeling to being able to be alive and thrive because of someone else's donation, you know, I think that helps. I think that would help a lot.

Pattern 2e: Lack of trust. P2 described the experience of becoming a registered organ donor despite traditional family values, as having to address the lack of trust for the system and wondering if wealthy people can jump the line to get organs first. African Americans have a lack of trust for the medical system; some of this can be contributed to racism and the studies that were performed on African Americans from the 17th century. Studies that are unlisted and those well documented include the Tuskegee experiment and the Henrietta Lacks story. It is with valid concern that African Americans have a lack of trust for the system.

“Growing up in the South and being African American is very difficult to...”

There's a big lack of trust. They didn't trust the system. They didn't trust a lot of people, and they probably wouldn't have, not probably, they didn't trust the idea that it would have gone to help somebody, the person who really needed the help as opposed to the person who had the most money to give. I think that's still a big factor in whether people choose to donate.

“I think there's still an idea that people can jump the line of who needs depending on how much wealth they have. That would have been one thing.”

“Plus, the biggest thing is they just really didn't, at that point, the 60s and 70s, they just didn't trust the system to do the right thing, especially since we lived in the South.”

Participant 3 P3. There were four patterns to emerge for P3. These four patterns were: (a) opposition, (b) can be useful to society, (c) money/convenience, and (d) don't trust the doctor. The patterns are described using quotes from the participant in the following subsections.

Pattern 3a: Opposition. P3 described the experience of becoming a registered organ donor despite traditional family values, as his wife opposes the decision to be an organ donor.

Being a registered organ donor was reported to be a touchy subject to discuss in his household. P3 reported that his wife was so against him being a registered organ donor that she will have him remove it from his driver's license upon renewal. P3 revealed his desire to keep his wife happy; however, he believes that her way of thinking about organ donation is "a little silly." Despite his feelings and desire to remain a donor upon his death, he will remove it from his driver's license.

"My family feels like if I [am] an organ donor that I will be put on the third or fourth list of survival. They feel like since I'm an organ donor, if I have a car accident or something happens, that the ambulance is going to want to get my organ instead of keeping me alive."

"She feels like I have a better chance of living in a car accident or motorcycle accident if I'm not giving my organs up."

"She does not want me to be an organ donor. Honestly, and it's a very touchy subject in the house. It's up there with rape, and religion, and women's rights. It's really tough. So, I most likely, pretty soon in the future I'm not going to be an organ donor."

So, the day I had to go to DMV I was gonna go by myself, but my wife, she actually got up before me and went with me. And she filled out the paperwork before we even got to the DMV that you do online. So, I didn't even know that she had did it until after I've taken a picture, gotten the temporary, and looked at it and said this doesn't have "donor" on it. I didn't even want to go through the process of even asking her or fighting with her about it.

P3 was a registered organ donor at the time of the initial interview. Two months later at the time of the follow up interview, P3 had renewed his driver's license and changed his organ donor status.

Pattern 3b: Can be useful to society. P3 described the experience of becoming a registered organ donor despite traditional family values, as wanting to be useful. The desire to help someone live longer by donating an organ after one no longer needs them is viewed as a

form of service by P3. It makes sense to donate the good organs to someone that can use them and not cremate the organs with the body if someone can use them and live longer. Save the life of someone who might otherwise die with this gift. The donor can no longer use the organs. Be of service and save a life is how P3 wanted to help.

“I just feel like I can be useful to society or to someone that needs an organ. If I lost my life really quick, I can be able to keep somebody else’s life going.”

I was 21, and I decided when I was going to play football and not go to the military, that I wanted to be able to give back somehow since I’m not fighting for my country. I feel like I could, at least if I died, give a liver or kidney or something to somebody who needs it, because I want to be cremated. So, I’m not using my organs anyway.

“It’s something that you definitely think about, like “Oh.” You see it on your license. I’m an organ donor. Like, what organ would they take if I die, you know? You kind of ponder the thought.”

“I feel like that’s the way I give, and you can’t tell me how to give when I’m dead.”

“Just people, in general, need it. If you’re an organ donor, you give them permission to give away your organ. So, it’s almost like a win-win, or we’re not worried about him. He’s going to help other people.”

Pattern 3c: Money/convenience. P3 described the experience of becoming a registered organ donor despite traditional family values, as saving money at the DMV. Being able to renew the driver’s license and consider the possibility of saving a life was convenient. The department of motor vehicles offered a discount for signing the organ donor card; this process gave several the opportunity to consider saving a life after. P3 described it as a winning situation, a discount on the driver license renewal, and the chance to help save a life too.

“Yeah, it’s cheaper if you’re an organ donor. I don’t know, five or 10 dollars cheaper.”

“I was like, “Oh yeah.” I think I was short one day going to the DMV, and I thought that would be cool, plus you can actually save a life. Yeah! That’s a good concept.”

“She’s a college student, so she’s my cheapest route. “You get a discount for your daughter.” “Uh- huh.” “You really do.” That’s one of my reasons for doing it (signing donor card at DMV). It’s like half the price.”

Pattern 3d: Don’t trust the doctor. P3 described the experience of becoming a registered organ donor despite traditional family values, as a lack of trust for the doctors. P3 described his wife’s fears that the doctors will give organs to somebody White and not try to save him if he is in a car or motorcycle accident. The concerns stem from a lack of trust his wife has gotten from her mother and being born in the 1930s, having experienced racism, and just not trusting White people and doctors. The wife’s lack of trust may force him to change his organ donor registration.

Well, when you’re talking about somebody that was born in the 30s, they tend not to even go to the doctor. They don’t trust the doctor. Sometimes the doctor is the “White man” and, you know, he going to find something wrong with you, so they can take your organs and give it to somebody who is White, so they can live. So, there’s this racial connotation to it from back and before Martin.

So, she believes that if I’m an organ donor, and you got Mary Sue or Barbara Joe, you know, pure White Americans who needed an, organ they will not save my life during an incident, and I would uh, they would just let me ride while they give the organs away to the people, so they can live, mostly White people.

“That’s that White people come before us, and if we were to donor off our organs, then we’re going to, they’re going to pass us up on life-living devices to give our organs away to some, somebody anglo that would need it.”

“So, with that theory, it’s only believed that we’re going to be last on the list anyway. I just had a, I just had an aunt, great aunt die, She was 75, but she was waiting on kidneys, and she never got her kidneys.”

Participant 4 P4. Three patterns emerged for participant 4, (a) thinking of changing registered organ donor status, (b) money/convenience, and (c) lack of trust.

Pattern 4a: Thinking of changing registered organ donor status. P4 described the experience of becoming a registered organ donor despite traditional family values, as thinking of changing organ donor status on driver's license. The girlfriend works in a hospital and believes that doctors will not offer their best efforts to save her if she is in an accident. However, she is not as adamant in revoking her registration but giving it, some thought. The girlfriend has shared some stories of accident victims coming into the hospital where she felt they could have spent more time working to save them; however, doctors "called it." These concerns and fears appear to have transferred to P4.

"I guess my significant other has made me, I guess, think more about it because I wasn't really thinking about it before, and she gave me a reason, I guess, to kind of put a little more thought into it, you know, because of the things she's said about it."

"Possibly, or not necessarily change, but at least give more thought into it because the reasoning behind me doing it...it was not."

"So, now, having people let her say her point of view on it gives me more, I take it more seriously and, you know, think about it, and let people know what's going on."

Yeah, I mean like, even though she doesn't agree, like, I mean like, it'll take me time to think and figure out if I still want to do it or not. Her perspective wouldn't be my end all, be all in making a decision, but of course, it would have to have some effect on that.

Pattern 4b: Money/convenience. P4 described the experience of becoming a registered organ donor despite traditional family values, as a discount. The department of motor vehicles offers a discount for adding registered organ donor on the driver's license. P4 explains that she

registered as an organ to receive the discount and that has not changed, because the renewal reduced the driver's license from \$20.00, to \$8.00. For P4, this was a significant saving at the time, and she has continued to allow the discount to be applied over the years.

Well, that's the thing. It's not like I had somebody that was sick or something, or I was reading and saw all the need of these people need this or that. It was because they said I could get a discount on my driver's license. And I said, 'Well it can't hurt. I can get some money off, and if they do go in and take it, then they'll save somebody hopefully.

"Yup, at the time, and it just hasn't changed. I just keep getting it renewed, and I ain't changed it. But yeah, you know, that was the reason why more than anything."

Well somebody told me before I was younger and, you know, struggling, so I had to pay \$25-\$20 or something to get the license, and somebody was like, "Hey, you become an organ donor it's like \$8 or something, \$15, \$12." So I said, "Really?"

Pattern 4c: Lack of trust. P4 described the experience of becoming a registered organ donor despite traditional family values, as a lack of trust. As previously stated above, African Americans have a deep-rooted lack of trust for the medical system and being an organ donor can impede chances of survival if, in an accident, doctors take an organ and give to someone else before trying to save the person's life. As previously stated, the girlfriend works at a hospital and believes that doctors could spend more time attempting to save lives when victims come into the emergency room.

"Just that they feel as though that organ donations mess up your chances of surviving if you actually have a little bit of chance of surviving. The doctors might not work on you, per se, as hard as they would somebody else that wasn't an organ donor."

Someone could be borderline, and instead of going the extra mile to help them possibly survive, they would cut it short in order to be able to take an organ and give it to someone else who you know is not, so they can have a chance to survive.

Participant 5 P5. There were four patterns that emerged for participant 5: (a) self-preservation, (b) indifference, (c) can help somebody, and (d) revoked registration.

Pattern 5a: Self-preservation. P5 described the experience of becoming a registered organ donor despite traditional family values, as self-preservation to save money and doing what is important to oneself. At the age of 17, saving money was of interest; however not all young people are focused on health. For P5, the discount given at the motor vehicles department was an incentive in her signing her donor registration card.

“My family always urged me to think, so there needed to be a reason more than just to save money.”

“If you want to save these amounts of dollars, then become an organ donor. That’s it. That was the entirety of my educational, you know, explanation of that program.”

“Oh, and by the way, I got to save money. I accomplished getting my license, and I saved some money.”

“I have changed my eating habits, but for me, not because of being an organ donor. So, me trying to do better is for my time while I’m still alive, not to preserve organs for someone while I’m not.”

Pattern 5b: Indifference. P5 described the experience of becoming a registered organ donor despite traditional family values, like indifference, and the family had mixed reviews about her becoming a registered organ donor. P5, described being a new driver, and the idea of saving money and getting her driver’s license was appealing. However, the family wanted her to have a clear understanding of the importance of her decision and to read up on why money/a discount may have been offered.

“I said indifference when I shared it because it wasn’t more so of round table discussion.”

“It was disappointing to a couple because again I was always taught to do something for more than...think more about why you’ve done this.”

“So, I was urged to read and learn and make an informed decision. I wasn’t told by everyone that this was a good thing or bad thing. It just was thinking more about why you’ve done this, not just ‘cause you saved a couple of dollars.”

Pattern 5c: Help somebody. P5 described the experience of becoming a registered organ donor despite traditional family values, as being able to help somebody. Passing organs on to save the life of someone in need was P5’s intention. Knowing that someone else can use the good organs she leaves behind was a good idea and she wanted to share the decision with her family. However, her family wanted to make sure that she had clear facts on just what that decision entailed.

Yes. That means if I get into a car accident or I die, then that means I can help somebody else because I can’t use my liver anymore, or I can’t use my lungs. Then, I’d be able to pass them over to someone else, and then there was more conversation, and they did more probing.

“My mother thought it was a good decision because she thought that we would be able to give our organs to someone that needed them once we did crossover, perished, and I had some that were indifferent.”

“If I die, then that means I can help somebody else because I can’t use my liver anymore, or I can’t use my lungs.”

Pattern 5d: Revoked organ donor status. P5 described the experience of becoming a registered organ donor despite traditional family values, as revoking organ donor status. P5 stated she has read of people waking up just as the organ procurement process has started. However, she believes that more people would support organ donation if they could choose the recipient of their organs and leave a directive to donate organs to someone of African heritage or the like.

“I changed that a few years ago because the more studying that I’ve done, I’ve learned that the tests that they do are not as evasive. Think it was a splash of cold water to see if your ears moved. The tests are very quick.”

“I’ve read several cases to where they’re either prepping for surgery or began, and that person starts to regain consciousness.”

“Just because I can’t speak doesn’t mean I can’t think, I can’t feel. So, I find that to be scary. So, the more reading I did, I immediately changed my status. I am no longer an organ donor, and I wouldn’t encourage anyone to be either.”

“I feel maybe some people would be more on board if they had a say in who would receive their organs.”

Participant 6 P6. There were five patterns to emerge for participant 6: (a) conversations, (b) helping people, (c) outreach to the religious community, (d) fear/afraid, and (e) decision.

Pattern 6a: Conversations. P6 described the experience of becoming a registered organ donor despite traditional family values, as being dominated by conversations about everything with several of the family members. However, many family members expressed issues with her decision and voiced their feelings by saying that it was not right, and it went against the church. In some conversations, her cousins attempted to change her mind about being an organ donor.

“I became an organ donor many, many years ago, and it wasn't my immediate family that had issues with it even though I think my father probably did. It was really extended family.”

“Mostly my mother, sisters, and a couple of cousins that had issues with, with that decision. And it's just because, and I didn't so much initially tell them that I'm going to be an organ donor; we just started having conversations.”

“But what I found with some of my, my mother, sisters, and my cousins, they pretty much felt the same way. They just felt that it was not the right thing to do that when we die, we need to be buried in the ground fully.”

“That doing those types of things that it was sort of like a sin, you know, and it went against the church, and they are primarily Baptist.”

Pattern 6b: Helping people. P6 described the experience of becoming a registered organ donor despite traditional family values, as helping people. P6 explains how her parents were always helping others, and this was instilled in her and her siblings. She explains that the type of help her parents gave to people that they did not even know, such as giving money or a place to stay was important. Therefore, to become an organ donor and to give organs she no longer needed, it made sense to her based on her parents giving and caring nature.

“If you can help somebody else, then you should, and then my also feeling about it is that once you’re dead, you’re dead.”

“If there's something that you have that can help somebody else, we should do that.”

That's just part of my immediate family values, in terms of the values that my parents put in us in terms of helping other people. I don't know if they thought about the organ donation thing because it was more about helping people on earth and doing all those things. But it just made sense. And it's like, is that something that can help somebody? And that's the way I was looking at.

Pattern (c) outreach to religious community: P6 described the experience of becoming a registered organ donor despite traditional family values, as communication, having discussions, conversations, and talking, wanting to have a discussion with the ministers in the community, and having discussions about organ donations as common as talking about cancer. P6 expressed that she wants the conversation to extend from her family to the community, to the ministers in the churches, and the congregations so that talking about being a registered organ donor becomes the norm, becomes common and increases. The hope is that the religious community becomes engaged and communicates the need.

“We just started having conversations like that, because, in my family, we have a lot of conversations about a lot of different things. So, we'd have conversations

about it. My feeling about it is that if you can help somebody else, then you should.”

“But you know, we've had conversations over the years. So, but prior to the organ donation, I honestly don't remember, if we had those conversations. I think we probably may have, but who knows.”

Since our community is so meshed in the church, if we could get the ministry on board with discussing organ donation during church services, or whatever the case may be, that could conceivably change some minds, especially in terms of taking your organs with you to heaven, or even some of the fears associated with it because since we do have ministers involved in politics, and telling how to vote, and a lot of them do what the ministers say.

“So, my hope is that, that it would be important enough that it is a conversation just like cancer is a conversation. Everybody is on the bandwagon about that, rightly so.”

I mean, the question's always asked when you renew your license, and I don't expect the DMV to do it, because that's not the right place for that discussion to be had. But in terms of they're already somewhere where there's church, where there's community, whether it's, you know, sororities having those discussions among their members, any organization that is heavily African American would, who would embrace this as one of their causes, then that may change some things.

Pattern 6d: Fear/afraid. P6 described the experience of becoming a registered organ donor despite traditional family values, as fear, just flat out fear, and if we are concerned about others, then more people need to step up. P6 explained that some people have a fear of becoming a registered organ donor. As previously stated, many experiments conducted on African Americans, and one fear that has been stated previously is that organs will be taken without attempting to save one's life.

“Some people are afraid. I mean, it just is a fear factor, and that is such an unknown, but death isn't unknown, you know, and they're not going to take your organs while you're still living. But if you are afraid, you are afraid.”

“But I do find for us that some of it is just flat out fear, and then, with others is just like, “Well, I don't care.” You know, and then okay, if you don't care, the next time you go get your license renewed just tell them to check the box.”

“If we say that we are really concerned about us as a people, and if we say all these other terrible things are happening to us as a people, then another terrible thing can be that somebody could die because we didn't step up with one small, simple thing.”

Pattern 6e: Decision-making. P6 described the experience of becoming a registered organ donor despite traditional family values, as decision making. P6 stated that we have got to do this, check those boxes that ask if you want to be an organ donor. Throw out fear and worry about needing your organs after death. The family is a significant factor to consider when making a decision that will eventually involve them, so have a discussion with them to inform them if you wished, make the decision, check the box, follow through on the decision and become an organ donor that is it because it makes good sense.

So, you know, if I see a post I immediately share, you know. We've got to do it. We've got to do it because we would want somebody to do it for our kid if we had one, or our niece or our nephew, or whatever, our mother or father, whoever.

You know, so now it is on the driver's license. It, you know, with the medical school, I want to say that when I signed off on giving my body away, I think that there was also a form that talked about donation, and I think I've checked those boxes.

Went ahead and just filled it out so that it wouldn't get lost in the mess on my desk. That's what I'm thinking. I honestly don't remember because it was so long ago. It really wasn't, it wasn't anything that I had to ponder on or think about, or walk away from and come back to, or angst over, or anything like that because it just made sense.

Participant 7 P7. There were four patterns to emerge for P7: (a) they think I'm crazy, (b) inspired, (c) revoking organ donor status, and (d) pride, accomplished.

Pattern 7a: They think I'm crazy. P7 described the experience of becoming a registered organ donor despite traditional family values, as they think I'm crazy. P7 thinks differently from many of his family members who have expressed that Black people do not donate organs.

However, P7 has moved away from his family, attained additional education and has been influenced by a Will Smith movie where he donated organs. Shortly after seeing the movie, P7 became a registered organ donor.

Okay? Um, of course, everybody thinks I'm crazy. They think that, well, let me give you some background. Since I've moved to [city redacted] and progressed in my career and my income, I don't think a lot like most of my relatives, and they say that I'm bougie. They say, they call me a Black Republican, although I've never voted Republican.

I had never had that discussion with family members, not even friends really. It was just always understood Black people don't, don't check that box, but afterward, like somebody might see my license and be like, "You're an organ donor?" And it would start a conversation. So, I mean it opened up the discussions. I think I opened some folks' eyes to certain things. But at the same time, I wasn't a strong enough proponent. I was just like, this is how I feel, you know, I'm not here to sell you on it, and I can tell you why I feel this way. But I wasn't about to sit down, and debate and try to change someone's mind. I had grown past that small-minded thinking.

When I made that decision and shared it with my family, I didn't share with them immediately. But when I did share with them, it was kind of like, "I'm not shocked that you would make a choice like that." And then they asked the question as to why you did it. And I said, stated that, I don't know if I'm jumping ahead to one of the questions being asked, but the movie, the Will Smith movie, I think it was called Five Pounds.

Pattern 7b: Being inspired. P7 described the experience of becoming a registered organ donor despite traditional family values, as being inspired. The movie, *Seven Pounds*, helped him gain an understanding of how his donation can help another person. In addition, he realized that the shortage and need for organs was a human issue, not a race issue. Furthermore, P7 described stories from a TV special of individuals who have donated an organ and had a connection to the organ recipient. The stories were inspirational.

The Will Smith movie, I think it was called *Five Pounds* [*Seven Pounds*]. That movie inspired me to do it because I mean, it wasn't a Black issue. It wasn't a White

issue. It was a human, human being issue and knowing that my organs could be used to help somebody else live or live longer and when they wouldn't be doing me any good in a casket. So, that was my decision behind doing it.

I mean, just giving, giving life to somebody else that they can use it, and, and also the inspiration like in the movie. It almost felt like he lived on through those people.

And I've seen stories online where people like, their family member died, their heart was donated to somebody and they may meet the person that their heart was donated to and listen to it. And it's, it's almost like they felt a connection to that person. Like that's my relative's still, still living in you. That was part of the inspiration that I, I felt initially when I made the decision to become an organ donor.

Pattern 7c: Revoking organ donor status. P7 described the experience of becoming a registered organ donor despite traditional family values, as revoking organ donor status. The family and fiancé are all worried and concerned about him being a registered organ donor and have attempted to talk him into changing his license. Although he is still a registered organ donor, he is considering a change to ease the mind of his loved ones. P7 is not necessarily fearful of the process of organ procurement, but he is concerned with his family's feelings and views. Therefore, he stated that he could allow the family to decide at the time of his death as to whether they are willing to donate his organs; that way the government is kept out of it and the family can decide.

“When I told her that I was doing this study, she was like, “Oh, you haven't, you haven't changed that yet. I thought we said you were going to change that.”

My renewal is 2020. So, I just know dealing with the driver's administration office, I don't want to go down there anytime soon. So, unless like my girlfriend, unless we got married, and she remembered this and said, “Hey as far as us being one union now, I would really want you to go down there and change that on your license right now,”

I'm not going to change it until my license expires because I've had some second thoughts based on some stories that I have heard recently that has made me second guess that decision.

Pattern 7d: Pride and accomplishment. P7 described the experience of becoming a registered organ donor despite traditional family values, as having a sense of pride, accomplishment. Graduating from college and moving away gave P7 a sense of pride, he believed that he emerged above the stereotypical thought that Black people do not donate organs or vote Republican. So, he signed to become a registered donor, he was proud and had arrived, moved to a new city, landed a big new job, a nice home and car, and left the state he lived in behind.

Probably was about two years ago, and at the very moment, I felt a sense of pride, accomplishment. I felt like was..., I had matured and grown as a person beyond the typical, the stereotypical Black person that is, 'Oh, Black people don't, don't donate their organs.' I feel like I had. I had graduated above that.

I feel like my parents or my loved ones can make that decision based on how, however they are feeling at that exact moment. I have a sister. She's two years younger than me. She, she does not. And she lives in [state redacted], so she has that [state] mentality. And like I said, this is like the fact that I'm going to change it back. I'm changing it back just to calm people's nerves, because I don't. Well, I guess 80% of it would be to calm my relative's nerves and my loved one's nerves. The other 20% might be to calm my own concerns based on the racist atmosphere in America.

It has opened up the discussion like I said, with family members. with loved ones, that they could make that decision after the fact; and, with them knowing, "Okay. He's gone."

So why do we need, once again, the government to be involved to say, "Oh, we, we got it right here. We're taken his organs. Now, you guys don't have anything to say about it."

That could be an even more upsetting situation for the family if they're told, "We're taking his organs because we have a right to" versus someone coming to

them and saying, “Hey, you know, he's, he's not, he didn't make it. And you guys need to make a decision. Do you want to donate his organs?”

If I knew that person was gone. Like hey, they say, you know, you can go in and say your final goodbyes. I went and did that, and I was at peace with the fact that they're gone, I would definitely donate their organs.

Participant 8 P8. There were five patterns to emerge from data for P8: (a) experience with kidney disease, (b) open communication, (c) self-preservation, (d) fear, and (e) resources.

Pattern 8a: Experience with kidney disease. P8 described the experience of becoming a registered organ donor despite traditional family values, as experience with kidney disease based on family members needing an organ transplant. Kidney disease was often mentioned in the family of P8 with several relatives suffering from kidney disease. P8 was aware of the pain and suffering that accompanied the illness.

I had a family member, my first cousins, their side of, their mother's side of the family, had kidney disease, and it was a strong family history. So, there were 12 siblings, and out of the 12, there were maybe four that ended up with kidney disease, dialysis, and eventually needed transplants.

So, that kind of was hard because then you don't know who else may develop it over time. So that was kind of different, you know, just seeing it firsthand and to see it so prevalent in one family. That's pretty much what shaped my beliefs and what changed my whole thought on the organ transplant.

Pattern 8b: Open communication. P8 described the experience of becoming a registered organ donor despite traditional family values, as open communication having open discussions within the family about members needing organs, looking for organ donors within the family, and missed family activities because of being sick. Family members being tested to see if kidney disease will affect them or see if they were a match to help another relative was a conversation often heard in the family. The missing family member from an event due to them not feeling well

or even the conversation of one receiving a transplant and taking care of one's health was another conversation of interest in the family. Communication within the family about organ donation was always on the tip of one's tongue in her family.

I think it started in our household a little bit earlier than normal because there were so many people, and they were testing the siblings to see who, you know, or other family members trying to reach out to see who may be a match so that they could get the transplants. You just wonder you know, "Will that be me one day? Will I need an organ?" So, it forces you to think about it and kind of have that discussion with your family.

So, I was just thinking, my mom, her youngest sister, was on dialysis. Unfortunately, she died, was never on the transplant list, but she had a lot of major medical conditions you know, they come to pick her up and take her to dialysis, and, but my mom never really discussed as far as the need for a transplant or her thoughts as it relates to her sister.

You kind of hear about it, and you're kind of like..., and then I think as it gets closer and closer to you, you know, as far as people you know, and you see the suffering, you kind of see things differently. You know, you can't, you know, you could take them with you, but what good is it if it could help, you know?

I remember many of family activities they couldn't attend because they needed to be on dialysis. And I remember when I was younger, it was not as convenient. They missed a lot of activities and events, and when you did see them, you could just tell, you know, that they weren't feeling well. So, it just, it's hard, especially when there's so many people in just one family, and they're like your first cousins. So it's really..., it's hard to watch, and it just kind of makes you think a little bit deeper. And I think it makes you do more research on your own to try to find out more about it, and as far as the process, you know.

Pattern 8c: Self-preservation. P8 described the experience of becoming a registered organ donor despite traditional family values, as the need to focus on one's own health, to be healthy if you are going to be an organ donor, to help others because you never know if you will need an organ transplant one day and to support organ donation. With all of the relatives that needed a kidney in the family, P8 was often concerned if it would affect her, and she would one

day need an organ. Therefore, she focused on her health, exercised, and practiced healthy eating habits to ward off kidney disease and to help others through organ donation.

You also focus on your own health, you know, in the event that you may have to because you never know. There are different things that prompt kidney disease or different diseases, where you may need a transplant. So, it makes you want to eat better and just do different natural things to try to help you, you know, be in the best health you can in the event that you're needed.

In order to be an organ donor, you have to be, you know, to a certain extent healthy, and that kind of goes back to my family members who had the kidney disease.

“So, you just think if you can be of help, you know, then that kind of persuades you and changes your mindset because you never know if it's gonna be you either who may be in need of one.”

To help others. Like I said before, you just never know if you're going to be, or somebody in your family is going to be in that position. And to me, it's such a small thing that if you can, living or not, it just makes sense.

“I am all for donation.”

Pattern 8d: Fear. P8 described the experience of becoming a registered organ donor despite traditional family values, as fear, P8 talked about her mother being afraid that if something happened and she was in the hospital that doctors might not do their best to save her. The mother's fear may stem from her mother, being born and reared in Mississippi and living through several racial events. Despite several family members suffering from kidney disease, she is aware of the importance of organ donors, however, has a fear of her own children being registered donors.

But it's still, I think it's just that fear that you sign the card, you go to the hospital, they're not taking care of you to the best of their ability knowing that hey, she donated her organs. And I think that's ingrained in her mind as well as what she was taught from her mother.

I think you hear in the news sometimes that they feel like if you're an organ donor, you go into the hospital, that they may not give you the best care, you know if the organs are needed for someone of another race sometimes. Or, I just think part of religion plays into it. So, it sounds like it comes from maybe their mom. So, it's kind of passed on a part of us the fear and just that, that's what they're, they've been raised to believe You, you, you are buried with your organs.

I think my mom, she does see the value in it and knows that it helps people and that whole part of it, but it's when it's closer to home, I think that's where it kind of shifts and they just don't, they just don't believe in it.

I guess a part of it. I don't understand. You know, and like I said, I just believe, you know, my mom is 80-something, and I just think that's where it was back then. And just their mindset has not changed. And they just feel like it's not something that they want to do. Like I said, I think some of it is just fear. And it was just a standard. It's what they did. And I don't think she's really had anybody close to her that have had to have a transplant either. So maybe that's, you know, a big part of it.

Pattern 8e: Resources. P8 described the experience of becoming a registered organ donor despite traditional family values, as having resources, being exposed to information about organ donation. P8 mentioned meeting a woman who was registering people for bone marrow. It was beneficial to have the process explained to her, to be able to ask questions and receive a clear answer that explained the process and procedure, provided some comfort and understanding for P8 being able to reference some statistics and see the need provided a better understanding as well.

I met a lady who was registering people to being bone marrow donors. So that was kind of my first into the whole donation, and whatever. So, she just kind of had a lot of statistics and just talked about how we're in need. And as a people, we don't tend to, you know, sign up that you can be a donor or whatever. I learned a lot from her. She had a lot of resources and just information. So, I signed up for that.

I talked to the lady about the bone marrow. So that was my first step in, and she kind of gave me some information, but I kind of followed up kind of doing my own research just to find out "How's it going to impact me?" and "Is something going to happen to me if I go in, you know?"

So, and as time goes on like I said, you see your cousins, first cousins suffering and doing the dialysis, and then it gets to the point where that's not helping anymore. I think the statistics are alarming. You know, if you don't know, you don't realize how many people are really in need; how many people are on dialysis; how many people each year just need and are going to need organs and different things.

It's just alarming at the number of people who are in need, and then I think too, once you see someone who suffers and goes down the line, I think that kind of changes your mindset as well.

Participant 9 P9. A total of seven patterns emerged for P9: (a) decision making; (b) a need to communicate; (c) spirituality; (d) personal choice; (e) good health; (f) the ability to help people; and (g) a feeling of I'm an organ donor, and this is why. The following subsections contain information on P9's responses related to each of these patterns.

Pattern 9a: Decision to become an organ donor. P9 described the experience of becoming a registered organ donor despite traditional family values, as something that just happened. Hearing that a person was in need of an organ, and if they did not get it, they would die left P9 feeling as though something should be done. P9 indicated it was an instantaneous decision and that he made the choice almost automatically when he was asked if he wanted to be an organ donor. P9 stated that the decision was obvious and that he had not needed time to think it over, nor did he discuss it with anyone before making his decision. P9 offered the following statements related to this pattern.

"I think it just happened because when I went to get my driver's license or my past driver's license, they asked me did I want to become an organ donor, and I just said "yes," and they gave me a little orange sticker."

You hear that this person has been on the donor list for so long, and if something don't happen, they're going to die or whatever the case may be... bone marrow or whatever. So, it's like information coming in at all time. And so, when I went to get my driver's license, they asked me about it. I said, "Why not?"

Pattern 9b: A need to communicate. P9 described the experience of becoming a registered organ donor despite traditional family values, as a need to communicate. P9 felt it was important to tell his family about his desire to be an organ donor. P9 believed that letting his family know of plans now will make any decisions easier at his death. P9 talked about the importance of his family knowing that he wished his organs be donated. P9 observed that at the time of death, family members are grieving and dealing with personal emotions, so if they are aware of the organ donor status, there is one less decision to make.

“So, my immediate family, which is my father, five brothers, and sisters, I don’t think they know; my fiancée and her reaction was, ‘Why you do that?’”

“Family members and all those who know me, know that I’m a giving person and I’m like more here to serve than to be served.”

“I have to tell my parents, my brother, and sister. So, if something does happen to me, they know that my organs are going to be donated.”

Now, she’s afraid that they’re going to do it, pull the plug beforehand, and some miracle happened, and I come back, and now my organs are gone, and I can’t do nothing with them. I don’t think the doctors are like killing so we can get his organs, so this person can have a better life.

“If someone else is on life support and they need an organ really bad, will the doctor pull the plug on me just, so I can die, just so they can get the organ?”

Pattern 9c: Spirituality. P9 described the experience of becoming a registered organ donor despite traditional family values, as spiritual. P9 believed that he could live on with his organs being given to help another person have a better life. P9 also believed that if God were to come back, and he needed organs that he had donated, then God would give him new organs and that his physical body only housed his soul. P9 offered the following responses to questions about organ donation and spirituality.

“My viewpoint on it is through them I continue to live, and that’s more of like a spiritual thing than anything else as my spiritual side says it’s something that I can give.”

He’s going to come back for the living and the dead. Now if you’re dead and your organs are gone, how can you live? I haven’t researched it spiritually, but my thing was I don’t think the physical body that my spirit housed, I don’t think I’m going to need that physical body.

“It’s more. It’s more, and not taking anything away from God Jesus Christ, but it’s almost God-like because you have that power to make somebody’s life better.”

Now, if I look at it that way, me giving somebody a better life, me allowing somebody to see, allowing somebody to live 20, 30 more years because of my heart, or my lungs, or whatever. If that’s not being close to God-like, I don’t know what is.

This is what I want to do because spiritually it’s what God and Jesus Christ want you to do. So, it’s an extension of them. More people should do it.

Pattern 9d: Personal choice. P9 described the experience of becoming a registered organ donor despite traditional family values, as the decision was a personal choice. P9 noted that he had been raised to make his own choices in life. P9 observed that an individual’s body might be the only possession that he or she can control. P9 chose what he wanted to be done with his organs upon his death, and he indicated that this choice was personal. P9 liked that the choice was within his control, and it was his decision and his alone to become a registered organ donor. P9 shared the following observations.

“My thing is, I’m open-minded. Everybody has their opinion, and that’s fine and good. It’s their choice. It’s my choice. Like I said, my parents raised me to make my own choices.”

I decided to go into the navy. I made a choice. I chose the navy. So whatever decision I made, whether it’s good or bad, I deal with the rewards or the consequences of it. You make a choice. Whatever choice you made, good or bad, it’s on you. Your decision will not only affect you, the missus, and the children, you have to deal with the consequences of it.

Pattern 9e: Good health. P9 described the experience of becoming a registered organ donor despite traditional family values, as good health. P9 noted that he enjoys exercising and eating right. As a result, P9 believes that he is in good health, and his organs would serve to help someone live a better life. Although he donates blood, P9 desires to give more. Exercising and keeping active will allow his organs to remain in good shape, and hopefully, his organs can be used to prolong someone else's life when he no longer needs them. Responding to questions about his health, P9 shared the following:

“So, my health is good. I haven't played recently, but my health is good. You hear it on the radio shows and like that ...the organ donor, blood, and everything like that. And I donate blood when I can.”

“I'm in good health for a man 66, and that's more because I enjoy exercising. I enjoy eating right, but sometimes you splurge.”

“My organs are in good health.”

Pattern 9f: Will help people. P9 described the experience of becoming a registered organ donor despite traditional family values, as based on a desire to be helpful. P9 stated that he is not a selfish person. He is willing to give of himself so that someone else can have a better life. P9 wants to make sure that someone else can live if he cannot. P9 believed that donating his organs can help make that wish to come to fruition if and when his organs are passed on to someone in need. P9 offered the following statements in support of Pattern 9f:

I really don't care as long as it helps somebody else who can benefit from them. He will give of himself for somebody else. He's the most reliable one in the family. He's helpful like that. So why not continue that helpfulness beyond my existence?

Like I said before, it's something that I can give to make somebody's life better. Why just put them in the ground and, and before they put me in the ground and I have these perfectly good organs, heart, lungs, liver, whatever the case may be. Am I being selfish to keep them to myself and be in the ground and let nobody benefit from them? I think that's being selfish. I'm not a selfish person.

My thing with this donation thing, I'm giving of myself that somebody can have a better life. So, I'm to fill that position. When I'm gone, somebody's going to have a better life. Somebody's going to be able to see. Somebody's going to have a heart, or whatever the case may be. I'm fine with that, and that makes me feel better wherever I'm at. I'm fine with that.

That somebody's going to benefit from my donation. That's beautiful, and I'm fine with it. I have the opportunity to donate my organs to somebody else that they life may continue on 10, 15, 20 years, 30 years from now. That's a beautiful thing. That's a beautiful gift.

Pattern 9g: I'm an organ donor, and this is why. P9 described the experience of becoming a registered organ donor despite traditional family values, as being able to explain why he is a registered organ donor. The experience of overcoming the traditional values in his family left P9 with a very clear understanding of why he had become a registered organ donor. P9 explained his mother's death had also shaped his desire to register as an organ donor. P9 stated that it was important for him to be able to tell his family not only that he is a registered organ donor but also why it is important for him to be a donor. P9 also mentioned that he now explains to his family that he was inspired by his mother's experiences, the movie *Seven Pounds*, his desire to help others, and his spirituality. P9 offered the following responses that contributed to this pattern.

“Will Smith did a movie about... And I think he had purposely found these people who needed these organs and made sure that they get these organs.”

“Okay, my mother passed, and I can't remember the disease that caused her life, but it had something to do with her lungs.”

Knowing that I can go now to my family members when we have a family get-together, a barbeque, or, you know, meeting for Thanksgiving or Christmas or whatever like that, and say I'm an organ donor and this is why.

Cross Case Analysis

After the within-case analysis was completed, the data were examined using a cross-case analysis to discover similarities between the participants' experiences. These connections were identified and clustered together with the patterns to form themes. The themes and meanings are presented in Table 2 and described in the subsections that follow.

Table 2. *Themes and Supporting Patterns*

Themes	Supporting Patterns
Family opposition	Negativity (P1) Family being really shocked (P2) Opposition (P3) Indifference (P5) They think I'm crazy (P7) Lack of trust (P2, P4) Don't trust the doctor (P3)
Communication with family is important	Communication is necessary (P2) Conversations (P6) Open communication (P8) Need to communicate (P9) Refraining from further discussion (P1) I'm an organ donor, and this is why (P9)
Goodness as motivation/Being helpful to people and society	Basic goodness (P1) Selflessness (P2) Useful to society (P3) Can help somebody (P5) Helping people (P6) Help people (P9)
Other positive motivation	Self-preservation (P5, P8) Inspired (P7) Pride, accomplishment (P7) Good health (P9) Spirituality (P9) Money/Convenience (P4, P3)

Table 2. <i>Themes and Supporting Patterns Continued</i>	
Themes	Supporting Patterns
Outreach to community	Community Outreach (P1) Knowledge resources (P2) Outreach to the religious community (P6) Resources (P8)
Negative motivation as part of the experience	Fear/afraid (P6) Fear (P8)
Status change as a result of lack of trust	Changing status (P4) Revoked registration (P5) Revoking organ donor status (P7)
Decision-making	Decision (P6) A decision (P9) Personal choice (P9) Experience with kidney disease (P8)

Theme 1: *Family opposition.* Theme 1 was family opposition. This theme was expressed as a family response questioning the decision to become an organ donor or a response of shock when participants verbalized to the family that they intended to register as an organ donor. Participants expressed that it was not easy to discuss organ donation with family members. Numerous difficult questions were posed, and negative comments were sometimes made as family members tried to change the participants' decisions to become registered organ donors. Some participants were not even able to share their decisions freely or get too far into the conversation before being exposed to negativity. In other cases where the family was indifferent, they simply wanted the participant to be aware of their decision.

Theme 2: *Communication with family is important.* The second theme was that communicating with family members about organ donation was very important to the participants. More than half of the participants agreed that communication was essential to ensuring their wishes regarding donation were carried out. Some participants had conversations

with family members to inform them that they were registered organ donors. Other participants expressed that they had certain family members who it was difficult to talk with about their decision to become a registered organ donor. As part of this theme, several participants indicated the importance of ensuring family members were informed about the participants' organ donation wishes. Thus, if anything were to happen, the participants' families would be aware of the individual's wishes and could take steps to ensure any viable organs were donated. Participants contributing to this theme recommended that people interested in organ donation take steps to inform their loved ones of their wishes and their organ donation status. These conversations can also help foster a discussion of the importance of becoming a registered organ donor.

Theme 3: *Goodness as motivation/Being Helpful to people and society.* Theme 3 indicated that many of the participants were motivated by a desire to do good for others. The ability to help others was a theme that appeared when the participants discussed the impact their organs would have on other peoples' lives. Many participants felt it was important to be of good use and help save the life of someone in need. Participants questioned the justification for refusing organ donation and asserted that if organs are in good working condition after an accidental death, then they should be used to save lives. Wanting to be useful, helpful, and give back to society was listed as important by several participants.

Theme 4: *Other positive motivation.* The fourth theme addressed other positive motivations for organ donation, including self-preservation. Patterns related to Theme 4 appeared when a participant was concerned with his or her health or worried that he or she might also eventually need an organ. Self-preservation also emerged as a pattern contributing to Theme

4 when participants registered to be an organ donor because they were offered a discount at the Department of Motor Vehicles office in their state. Several participants indicated they were able to save money in the process of registering to be an organ donor. P3 described the discount on their driver's license as a "win-win, get a discount, and save a life." In one instance, the discount appeared to be the first motivation, and the ability to save a life seemed secondary.

Theme 4 incorporated several diverse patterns. Another pattern that emerged in one participant's responses was a sense of pride that issues surrounding race and fear did not negatively influence his decision to register as an organ donor. This participant described the need for registered organ donors as a human problem, not as a Black or White person issue. The desire to help someone, and save a life, to have the good organs used, and not to be put in the ground motivated most participants. The participants felt that saving a life and keeping someone alive was worth the effort to overcome traditional family values.

Theme 5: *Outreach to community.* The fifth theme that emerged from the cross-case analysis was that outreach to the community is vital. Participants indicated that having access to someone in the medical field made it easier to explain the need for organ donors. Participants noted the lack of information available in schools about becoming an organ donor. Several participants had never even considered becoming an organ donor before being offered a discount at the Motor Vehicles Department for registering to be an organ donor. Participants suggested that understanding the demand and the registration and donation processes would encourage more individuals to consider organ donation. Some participants recommended that religious communities make efforts to become more engaged in the hope that if the churches get involved

in educating the community, more African Americans might be willing to sign the organ donor card.

Theme 6: *Negative motivation as part of the experience.* Theme 6 indicated that there were also negative motivations related to organ donation. These negative motivations included fear of doctors and fear that the organ would not go to the person that needed it most. There was even suspicion that individuals would be able to purchase organs or be given higher priority for an organ based on their race. Multiple participants spoke of racism and living in the South as a basis for this fear. Participants observed that many African Americans do not trust the medical system. Several participants felt that doctors would not give 100% to save an African American if a White person needs an organ.

Theme 7: *Status change as a result of a lack of trust.* As a result of fear related to the medical system, a separate theme emerged related to participants' lack of trust in doctors. Theme 7 indicated that some participants considered changing their status as organ donors after listening to their family's fear and lack of trust with the organ donation system. Participants indicated that the arguments their families made that were most persuasive were the fears that organs would not go to the correct recipients or that doctors would not work as hard to save an injured person in the hopes of harvesting their organs for wealthy transplant patients. As a result, several participants' families attempted to convince organ donors to change their minds regarding organ donation.

Theme 8: *Decision-making.* The final theme that emerged from the cross-case analysis was that the decision to become an organ donor is not an easy one for African Americans. Some participants shared that they are rethinking their decision to be a registered organ donor due to

family influence. One participant had already changed/removed the organ donor registration from his driver's license at the insistence of his wife. Another participant was giving serious thought to removing the registration as well based on family members' fears for the participant's safety or survival in the event of an accident. Some participants had considered changing their registered organ donor status based on family concerns. However, many participants noted that organ donation was a personal choice that had both positive and negative consequences. Having family members who have lived with kidney disease and being taught to make their decisions was a strong motivation for some participants in favor of organ donation. Regardless of whether motivations and influences were positive or negative, Theme 8 indicated that family members played an important role in the decision-making process.

Summary

The sample consisted of nine African American participants over the age of 18. The participants were registered organ donors with the department of motor vehicles and willing to participate in this study. Participants were recruited using social networking and were randomly selected. The participants were interviewed to help answer the research question: "How do African Americans who have chosen to become registered organ donors describe their experience, despite traditional family values?"

The interviews were recorded, transcribed, and analyzed. A within-case analysis was used to examine individual participant's experiences. During this process, transcripts were analyzed to identify meaning units that were then grouped to represent patterns. When patterns were formed, a cross-case analysis was conducted. The cross-case analysis grouped similar patterns to develop themes.

A total of eight themes emerged from the cross-case analysis: (a) family opposition, (b) communication with family is important, (c) goodness as motivation/being helpful, (d) other positive motivation, (e) outreach to community, (f) negative motivation as part of experience, (g) lack of trust in the medical system, and (h) decision-making. These themes revealed the experience of the nine participants who have chosen to become a registered organ donor. The meaning of the themes and their relation to the research questions is discussed in greater detail in Chapter 5.

CHAPTER 5. DISCUSSION, IMPLICATIONS, RECOMMENDATIONS

Introduction

Chapter 5 contains a discussion of the results, limitations, conclusion, and recommendations for future research resulting from this study's findings and research question. The recommendations from the findings will help provide an understanding of the barriers that inhibit African Americans from becoming registered organ donors. The data and the results of case study analysis were revealed in Chapter 4, and in this chapter, those results were interpreted to determine the implications for further research regarding organ donation among African Americans.

Summary of the Results

This study was conducted to examine the experience of how African Americans who have chosen to become registered organ donors describe their experience, despite traditional family values. The research question fits into a qualitative, explorative arena, which focuses on a real-life phenomenon. The phenomenon investigated through this research was the conflict that may occur when an African American person has chosen to become a registered organ donor and experiences resistance from the family regarding their decision. This research is significant because a real-world problem that was examined, and the deficiency of available organs for successful transplants makes this study imperative. The premises also pointed to the study's significance in the field of general psychology as they examined family systems and altruistic behaviors. The theoretical framework for this study consisted of Kohlberg's (1958) and Gilligan's (1982) moral development theories, which focused on the moral dilemma of decision-making, and Bowen's family system theory, which provided insight into the weight of a family's

influence when an individual decides to donate an organ (Kerr, 2000). Furthermore, the sociocultural framework for this study was constituted by a culturally informed approach to positive psychology. The culturally informed approach to positive psychology focuses on the strengths and values of racial minority groups while having a significant ability to positively influence the psychological well-being of the group (Chang et al., 2016). Agreeing to become an organ donor falls into Kohlberg's (1958) and Gilligan's (1982) theory of moral development, which includes three levels of moral reasoning: pre-conventional, conventional, and post-conventional.

Stake's (1995) qualitative methodology model was used in this qualitative case study. The participants were recruited using purposeful sampling from various social networking sites. Most participants were from the southeastern part of the United States. This type of recruiting is appropriate for a qualitative case study, according to Stake (1995). In a case study, data may be gathered from multiple sources. The primary form of data collection consisted of interviews, an informal semi-structured interview process characterized by a conversational style of question and answer where participants were asked open-ended questions. During the interview, the participants' tone of voice and attitude was monitored. P1 appeared more inquisitive and interested in information about the research and what might be found. P6 was interested in getting involved in spreading the word to increase organ donors and appeared very motivated and eager. Other attitudes noted were from P9, who appeared very direct and serious regarding the way he explained his experience. The interviews were recorded, transcribed, and analyzed. A within-case analysis was used to examine each participant's transcribed interview to identify meaning units, then grouped to represent patterns. When patterns were formed, this researcher

began the cross-case analysis, which included similar grouping patterns to develop themes. The need to determine the consistency of findings was relevant. Therefore, triangulation was an intricate function. Stake (2010) described triangulation as “various habits” (p. 123), researchers use to get the meanings straight. However, “triangulation is the convergence of data collected from different sources, to determine the consistency of findings” (Yin, 2014, p. 241). The nine African American participants offered very intimate depictions of their experiences of being registered organ donors. Their stories described the adverse reactions, responses, and treatment they received from family and loved ones. The intimate depictions revealed a holistic perspective and a deeper understanding of the conflict that African Americans who have chosen to become registered organ donors have experienced.

From the cross-case analysis, eight themes emerged:

(a) Family opposition, which included questioning and a desire to change the mind of the registered organ donor by family and loved ones,

(b) Communication with family. Communication with family members. There is a need to tell or inform loved ones of the donor’s end of life desire to donate organs,

(c) Goodness as motivation. This was being helpful, specifically the desire to be of help to someone and save a life,

(d) Positive motivations-- being concerned with one’s own health, and concerns of whether an organ transplant will be needed in the future,

(e) Outreach to community. Outreach consisted of getting the information and knowledge out, to spread the word, having someone in the medical field to explain the need based on statistics and the process,

(f) Negative motivation. There is a fear that the organ will be given to the highest bidder, not the one that needs it and is on the waiting list,

(g) Lack of trust in the medical system. It was stated that the doctors being White will find something wrong, and he or she would not work to save the patient but allow him or her to die just to harvest organs,

(h) Decision-making. Some participants were at the point where they were either considering changing their registered organ donor status or had recently changed their status due to family fears and concerns. In contrast, another participant was reared to make his own decisions and wanted to make sure that his choice would be carried out upon his death to donate his organs. These themes revealed the experiences of the nine participants who have chosen to become a registered organ donor despite traditional family values and against their family's wishes.

Discussion of the Results

This study's findings provide awareness of the ongoing dilemmas that are apparent in the African American culture that prevent an increase in the number of registered organ donors. The themes that emerged from the case study analysis included the fact that communication with the family was reported as important so that the family will understand the organ donors wishes and grant the wishes at the end of life. In addition, based on the family's opposition, there are both positive and negative motivations that influence organ donors. However, the most important motivation appeared to be that it was good to help others. Outreach to the community and a lack of trust for the medical system were also concerns. These themes revealed the experiences of the

nine participants who have chosen to become registered organ donors despite traditional family values, and against their family's wishes.

The current study revealed that when African Americans choose to become registered organ donors, they face ridicule and negative responses from loved ones. The ridicule could interfere with the decision and, in some cases, cause one to change his or her mind about checking that box at the motor vehicles department when asked if he or she would like to be an organ donor. Also, although communication with family was a prominent theme among the participants, relaying the wishes of being an organ donor appeared stressful for some participants because family reactions were very negative or their family was shocked. These reactions could hinder further discussion about being a registered organ donor. Furthermore, the study revealed that several participants wanted to do something good, to help someone else, so they became registered organ donors to give back to society, as described by one participant. This reveals altruism and the desire to invest in and save another human being if possible. Outreach to the community was another dominant theme in the study. Robinson et al. (2014) conducted a study that revealed organ donations often conflict with religious beliefs among African Americans. However, churches may need to get involved in spreading the word regarding the need for African Americans to become registered organ donors. The churches could dispel some of the fears and concerns regarding organ donation and the need to have organs in place to enter the kingdom of God, as suggested by one participant.

Furthermore, if the religious community and the clergy are lacking the desire to get involved in dissemination of information about organ donation, another source of information could be the funeral home staff and directors. Some of the participants in this study were

influenced to become registered organ donors through the media and movies such as the Will Smith movie *Seven Pounds*. Therefore, spreading the word through movies, commercials, and social events embedded into other forms of entertainment may gain the interest and attention needed to make a positive impact.

A lack of trust for the medical system was another prominent theme in this study; however, a lack of trust in the medical system among African Americans is deeply rooted because it has been passed down from generation to generation and reinforced through racism. Many African Americans are aware of the Tuskegee syphilis experiment of 1932-1972 when several African American men were injected with the syphilis virus as a part of a study (Green et al., 2011). Another incident that is often cited as one that causes distrust in the medical system is the Henrietta Lacks story and her experiences at Johns Hopkins Medicine. She was a young African American woman who died of cervical cancer, and her cells were used all over the world without her family's knowledge (Skloot, 2010). These stories are prominent examples that invoke fear and a lack of trust in the African American community for the medical system. However, all of the fears can be allayed with positive information about organ donation, including statistics and valid examples provided by someone who looks like them and has a history similar to, or the same as theirs. In other words, African Americans need to be spreading the message and the examples of how organ donation has helped other African Americans in an effort to increase their rate of organ donation.

Conclusions Based on the Results

Based on the U.S. Department of Health & Human U.S. Government Information on Organ Donation and Transplantation (2019) Organ Donation Statistics, 83.4% of the people on

the national donor registry are awaiting a kidney transplant, and of that number 33.6% are African Americans. Furthermore, in 2015 there were a total of 30,969 kidney transplants with African Americans receiving a mere 6,755 (21.8%) and Whites receiving 17,179 (55.5%) of the transplants (OMH, 2016). In addition, African Americans have traditionally been reluctant to donate organs (Minniefield et al., 2001). African Americans disproportionately suffer from high blood pressure and diabetes, both of which cause damage to the kidneys and other organs (Martins et al., 2012).

The subject of African Americans and organ donation is of interest to community leaders, medical staff, counselors, the government, the media, Department of Motor Vehicles, psychologists, and the field of positive psychology. The study can shed light on how traditional family values play a significant role in decision making and the decision to become an organ donor, which can influence the way African Americans are approached to become donors.

Comparison of Findings With Theoretical Framework and Previous Literature

Comparing the findings from the current research to previous research, communication with the family was reported as critical. This supports the Bowen family systems theory in which the family is described as being hugely influential and as a unit that affects how each member thinks (Bowen, 1966, 1978; Kerr & Bowen, 1988). Furthermore, within the current research, some participants considered changing their registered organ donor status based on the family's opinion and concerns. Additionally, based on the family's opposition, there is positive and negative motivation to become an organ donor; however, the most important motivation was that it is good to help others. This was supported by Batson (2011) regarding altruism and empathy, that just wanting to help someone could cause an individual to step outside the traditional family

values and become an organ donor. However, TRA (Fishbein & Ajzen, 1975) and the TBA (Ajzen, 1991; Ajzen & Fishbein, 1980, 2005) were also significant regarding family communication and important in the decision-making process. This appeared in the current study as relevant when a participant revealed to the family that they were a registered organ donor and based on the family members' response, the participant either considered changing the organ donor status or considered having a conversation with the family members to make sure that their wishes would be granted and the organs donated.

The theoretical framework for this study was formed by a culturally informed approach to positive psychology and the moral development theories of Kohlberg (1958) and Gilligan (1982). Kohlberg and Gilligan focused on the moral dilemma of decision-making, as well as Bowen's family systems theory, which provided insight into the weight of a family's influence when an individual decides to donate an organ (Kerr, 2000).

Some of the themes parallel previous research findings regarding communication, lack of trust in the medical system, and outreach to the community. As has previously been reported in this research, family communication has been, and will remain, an intricate part of the organ donation process (Morgan, 2004), and has been identified by more than half of the participants as crucial. Furthermore, a lack of trust in the medical system was reported in previous research. As reported by Novotney (2011), many African Americans were fearful of donating organs solely based on a lack of knowledge surrounding the process and an underlying belief that doctors would allow them to die solely for the benefit of harvesting their organs to transplant. A statement such as this one was revealed in the current research. Some African Americans are concerned with body disfigurement for traditional funeral purposes and are less informed of the

organ donation process (Richard et al., 2007), which was also a relevant theme in the current study. Furthermore, regarding knowledge and resources in the community, a study revealed that African Americans receive information about organ donations through passive methods, such as popular entertainment, community organizations, and literature provided by the motor vehicles department when receiving or renewing the driver's license (Long et al., 2012). This supported the need for outreach in the community, which was a theme in the current study.

A recent review of the current literature on African Americans and organ donations included an article by Symvoulakis, Markaki, Anyfantakis, and Rachiotis (2018), which contained information regarding rethinking media campaigns for organ donation awareness. In this letter to the editor, the authors posited that one size does not fit all when it comes to spreading the word about organ donation. In an effort to increase registered organ donors, new types of messages need to be implemented, such as “grassroots and face to face efforts along with targeted health messaging through culturally relevant outreach materials” and a “media campaign targeted to affect knowledge, perceptions and attitudes” (Symvoulakis et al., 2018, p. 1165) in an effort to educate people and increase the number of registered organ donors. A search of the Capella University library PsycARTICLES and ProQuest Central provided limited information on new studies conducted since the current study began that relate to African Americans, organ donation, and the traditional family.

Interpretation of the Findings

In this study, the participants appeared aware of the dilemmas that affect the African American community based on their experiences with family and the initial attempt to communicate that they are registered organ donors. The results of this study support the results

that exist in previous studies such as African Americans are reluctant to donate, and it was found that when an African American has decided to become an organ donor, communicating their decision to family members was reported to evoke fear and can be problematic (Long et al., 2012). Furthermore, communication with family is necessary; the communication of the desire to donate is needed. Without the additional posthumous consent of the family, organ procurement by some agencies will not be processed despite having a donor registration card on file (Long et al., 2012). Fear of the medical system was still a relevant concern and getting the word out and the religious community involved to spread the word could create positive results. To make a significant increase in numbers, clergy, social workers, and community educators can play a meaningful role towards the motivation to become an organ donor in the African American community (Arriola et al., 2007). Demystifying the organ donation process can be achieved through education and by listening to the stories of donors, such as what motivated them to become a donor, and their experiences (Allen & Reese, 2016). Although the participants found it difficult to have a discussion with family, they did agree that it was a necessary task.

The finding that participants became registered organ donors out of their own goodness supports the previous findings of altruism in organ donation, which is wanting to help someone and give back to society through organ donation. Yousefi et al. (2014) reported that altruism is the most significant element in organ donation. However, this study adds another dimension when it comes to decision-making. P6 stated that we have got to do this, check those boxes that ask if you want to be an organ donor. Throw out fear and worry about needing the organs after death. P9 stated the decision was obvious to him “yes, no need to talk with anyone, no need to think about it, give me the orange sticker.” Based on the Bowen systems family theory of human

behavior, which considers the family an emotional unit that truly affects how people think, the way African Americans communicate could also influence decision-making (Kerr, 2000).

Notably, one new finding that this study revealed was the need to focus on one's own health; to be healthy if you are going to be an organ donor, to help others because you never know if you will need an organ transplant one day and to support organ donation based on self-preservation. However, this could be a motivation based on one's own experience with kidney disease within the family.

Limitations

This study was conducted to understand the experience of African Americans who have chosen to become registered organ donors despite traditional family values. This study consisted of nine participants who self-identified as African American registered organ donors, have experienced some conflict or disagreement with family about becoming a registered organ donor and were willing to participate in this study and share their experience. The limitations of this study revealed the fact that the participants provided self-reported responses that could have been underreported experiences or overstated to some degree. Emotions and true feelings regarding an experience could be painful to articulate or even overly expressed. In this case study research, the first limitation included a low number of participants from a limited geographical area. Stake (1995) claimed that a significant amount of information could be gained through a small group of participants, and although right for the current study, a more significant number of participants could enrich the breadth of findings. The participants were all over the age of 30 and were college educated with some knowledge of the need for African American organ donors. What could have skewed the results, to some extent, were the participants' experience of knowing

someone in need of a transplant, having knowledge of statistics for individuals in need of an organ transplant, and knowing someone in the medical field to help explain the organ donor process. The researcher analyzed the data over several months to thoroughly understand the participants' experiences. According to Stake (1995), "the objective of case study research is particularization, not a generalization and that particularization is relevant when a phenomenon is studied in-depth for understanding overall an extended amount of time" (p. 8).

Implications for Practice

This study provides valuable information about the experiences of African Americans who have chosen to become registered organ donors despite traditional family values. Significant practical contribution of the present research is that it provides much needed empirical data on the actual experiences of individual participants, which allow for identifying the barriers to African Americans becoming registered organ donors and how African Americans think about the organ donation process. This study can be used to shed light on how traditional family values play a significant role in decision-making when it comes to the end of life discussions by the medical team in hospitals. Portions of this study can provide an approach to addressing potential registered donors with the motor vehicles department, as well as provide insight to assist communication with family members. Counselors, clergy, and other professionals may use the findings of this research as a blueprint when discussing the decision to become a registered organ donor with African Americans. The media may also discover that these findings can be beneficial with organ donor recruitment at the Department of Motor Vehicles office. In addition, as psychologists work to change the misconceptions surrounding organ donation, this research may assist with family communications regarding organ donation decisions.

Recommendations for Further Research

Future research should be conducted to investigate a way of combating negative views of organ donations procedures, including concerns of medical staff, allowing one to die in order to harvest organs. Further research can be conducted to investigate how to spread the word about the need for African American registered organ donors as well as how to dispel the current myths about body snatchers and organ harvesting that are circulating within the community. A quantitative study can be conducted using the themes developed in this research to examine similar experiences.

Additional studies could be conducted to gain a perspective of African American potential organ or registered organ donors with a younger population than the current studies included. A study conducted with college students may be beneficial and provide a different perspective. All of the participants for the current study were over the age of 30, with some college education. Future studies might benefit from a broader arena of viewpoints, as well as an age difference among participants to provide views from a younger generation.

An important finding was that most of the participants indicated communication with family was necessary; therefore, additional studies can be conducted to investigate communication within the African American family. Furthermore, there are few studies on African American family dynamics, and future studies can be directed to include African American family dynamics, communication, and traditional family values. As previously mentioned, the Capella University ProQuest Central, PsycArticles, Psychology database, Psych database, and PsycINFO databases were used to search the following terms: *African American, organ donations, traditional family values, African-American communication, altruism, moral*

development, and *beliefs*. The keywords used to locate the peer-reviewed research articles that comprised the literature review contains limited information from new studies and articles.

African Americans continue to suffer from high blood pressure, which can lead to renal failure and the need for a kidney transplant. Are the numbers of kidney disease cases increasing or being reduced with medical techniques among African Americans? This could be a question for another area of research that could provide viable information within the research arena concerning African Americans and organ donation.

Conclusion

In conclusion, this study was undertaken to answer the research question: “How do African Americans who have chosen to become registered organ donors describe their experience despite traditional family values?” There was very little information in the extant literature regarding African American family values and traditional family values, in general, within the African American culture. The study was a qualitative case study, which used the Stake (1995) model of case study research. The sample consisted of nine African Americans who met the research eligibility requirements and were willing to participate in the study. The data were analyzed within individual case analysis, which consisted of finding patterns within each case data, and cross-case analysis that examined the data from all participants across cases. The case study analysis yielded eight themes: (a) family opposition, (b) communication with family is important, (c) goodness as motivation/being helpful, (d) other positive motivation, (e) outreach to community, (f) negative motivation as part of experience, (g) lack of trust in the medical system, and (h) decision-making. These themes revealed the experiences of the nine participants

who have chosen to become a registered organ donor despite traditional family values, and against their family's wishes.

The results of this study can be used to help understand how traditional family values play a significant role in decision-making when it comes to the ending of life discussion by the medical team in hospitals. Portions of this study can provide an approach to addressing potential registered donors with the motor vehicles department, as well as provide ways to communicate with family members. The media may also find that these findings can be beneficial with organ donor recruitment at the Department of Motor Vehicles office. Hopefully, this study will aid in understanding the impediments that stand in the way when an African American decides to become a registered organ donor so that the barriers addressed in this study will be overcome and the number of African American donors will be increased.

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