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The Role of Mistrust in African American Organ Donation

Gina M. Williams
Walden University

Walden University

College of Nursing

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Gina M. Williams

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Dr. Janice Long, Committee Chairperson, Nursing Faculty
Dr. Maria Ojeda, Committee Member, Nursing Faculty
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Sue Subocz, Ph.D.

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Abstract

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MSN, Walden University, 2016

BSN, DePaul University, 1991

Dissertation Submitted in Partial Fulfillment
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Abstract

African Americans (AAs) who suffer from life-threatening organ failure often need an organ transplant to sustain or to improve their quality of life. The shortage of donor organs, and AAs willing to become organ donors, limits the number of organs available for transplant. The purpose of this study was to understand the lived experience of AAs regarding the role of mistrust and to understand its influence on their organ donation decision-making. Social cognitive theory guided this qualitative descriptive phenomenological study designed to gain an understanding of the lived experiences of the AAs related to the role of mistrust in their organ donation decisions. Recruitment of the two male and six female participants was achieved through responses to flyers posted on social media and the Walden University participant pool. Participants were AAs,18 years of age and over with two participants having an organ donor card. Interviews using open-ended questions were conducted telephonically and transcribed manually then analyzed using thematic analysis. Five themes emerged from the analysis, trust in AA providers, feelings of mistrust, transparency, lack of understanding, and a pessimistic view of organ donation. Participants personal experiences with the healthcare community reinforced their feelings of transparency, mistrust, and an unwillingness to be organ donors. The results of this study may promote positive social change as healthcare professionals develop strategies to address the lack of transplant knowledge and AA's fears regarding organ donation, thereby improving organ donation in the population. Future interventional studies are needed to address the lack of transplant knowledge among AAs and to improve trust in healthcare providers.

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Dedication

I would like to dedicate my research to the two most influential women in my life, my mother Lena and grandmother Bernice. Both instilled in me the value and importance of education. Thank you, I love you, and will forever be indebted to you for the sacrifices you made to support, encourage, and nurture me in whatever I chose to accomplish.
Your lives are an example of kindness and strength that taught me to be kind to others and to never give up even when things looked impossible. Your love of God taught me to have faith and believe, that with God, all things are possible. I believe this, because this dissertation is proof.

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To my husband and best friend Maurice, I love you and I am so grateful to you for your patience and understanding during this journey. Thank you for all the times you listened to me, even when you did not understand what you were listening to.

To my friends and family, thank you for your love, support, and encouragement.

Table of Contents

Chapter 1: Overview of the Study

Introduction

African Americans (AAs) represent 13% of the entire United States population and disproportionately account for 29% of patients waiting for an organ transplant (Organ Procurement and Transplantation Network [OPTN], 2019; Robinson et al., 2015). AAs make-up 29% of the transplant list and account for approximately 13% of the registered organ donors (U.S Department of Health and Human Services Office of Minority Health [OMH], 2016). It is uncertain why there continue to be disparities between the growing numbers of AA patients waiting for donor organs and the actual number of organs available for transplant.

Medical mistrust is a key barrier to AA willingness to become organ donors (Arnett et al., 2016; Kinlock et al., 2017). Medical mistrust is defined as a lack of confidence in the intentions and motives of the United States (U.S) medical community (Hammond, 2010). Mistrust involves negative perceptions or suspicions of an individual health care provider or an entire health organization (Hammond, 2010). Past and present medical and social inequities account for the negative attitudes and perceptions many AAs have of the medical community (Hammond, 2010). These negative perceptions have resulted in distrust of the medical community and their continued reluctance to consider becoming organ donors (Arnett et al., 2016; Kinlock et al., 2017). I sought to understand the role of AA mistrust in organ donation decision-making and identify why these negative perceptions continue to remain so prevalent in the AA community.

Using qualitative interviews to understand the lived experiences of AAs, this research represents a positive step towards improving negative attitudes and perceptions that currently influence AA decisions to become organ donors. Improving organ donation in the AA community is instrumental in providing the life-changing medical care needed to improve the health of AAs suffering from acute and chronic illnesses. Chapter 1 will include the study's background, problem statement, purpose, research question, theoretical framework, nature of the study, and its significance to this population.

Background

Acute and chronic disease endanger the quality of life and well-being of the AA community, resulting in adverse health outcomes (Robinson et al., 2015). The need for organ transplants in the AA community is far above the number of donor organs available (Robinson, et al., 2015; Williamson et al., 2017). There are several factors that contribute to the low rates of available donor organs and organ donors. African American need for donor organs is higher than other ethnicities because of higher incidence of heart disease, hypertension, renal failure, and diabetes (Robinson & Arriola, 2015; Robinson et al., 2015; Williamson et al., 2017). The difficulty in finding matched organs decreases the availability of donor organs (Robinson et al., 2015). Histocompatibility issues stop many AA patients from using donated organs from other ethnicities, increasing the urgency to improve the donation rates and the availability of donor organs for the AA community (Quick et al., 2016; Robinson et al., 2015; Williamson et al., 2017). Despite increased awareness of the health disparities and need for more AA organ donors, many AAs continue to be unwilling to consider organ donation (Williams et al., 2017). Unethical medical experimentation, racism, and historical mistreatment committed against AA people, are some of the reasons AAs are unwilling to become organ donors (Hammond, 2010; Robinson et al., 2015; Williamson et al., 2018).

There is a long and dysfunctional history between AAs and healthcare. There is a persistent negative relationship between AAs and the medical community since the 18th century (Williamson et al., 2018). The Tuskegee syphilis study is the most widely known unethical medical experiment committed against AAs. African American men suffering from syphilis were purposefully not treated by the American government to provide doctors with the opportunity to observe and understand the progression of the disease (Williamson et al., 2018). More recently, the medical community has come under scrutiny for their failure to acknowledge medical advances resulting from the stolen cervical cells of Henrietta Lacks, a 31 year old AA woman who died from cervical cancer in 1951 (Skloot, 2010). As a historically oppressed people, the AA experience involves trauma and pain. Past social and racial injustices have contributed to the continued negative attitudes and beliefs that permeate current AA suspicion and mistrust of the medical community.

Ethical guidelines for clinical research established by the National Institute of Health (NIH) between 1947 and 2002 are a response to the past abuses of the medical community (Smirnoff et al., 2018). These guidelines now influence and govern all present and future medical and research practices to prevent further mistreatment in the AA community. However, despite changes in guidelines governing medical and research practices, there continues to be a high level of unresolved mistrust within the AA community that may influence their decision to volunteer for organ donation (Williamson et al., 2017; Williamson et al., 2018).

Medical mistrust is defined as the absence of trust or a suspicion or sense of unease in the intentions of a health provider or organization to act in the best interests of the patient (Hammond, 2010; Kinlock et al., 2017; Smirnoff et al.,2018). Medical mistrust is a critical determinant in AA reluctance to volunteer for organ donation (Quick et al., 2016; Robinson et al., 2015; Williamson et al., 2017; Williamson et al., 2018). The historical roots of medical mistrust are significant and noteworthy, and continues to be a dominant, negative perception in the AA community, resulting in fear and suspicion, preventing many AAs from becoming an organ donor (Arnett, et al., 2016; Hammond, 2010; Kinlock et al., 2017; Quick et al., 2016; Robinson et al., 2015; Williamson et al., 2017; Williamson et al., 2018). The AA community has internalized their lived experiences regarding these negative events and are socialized throughout the generations to mistrust the medical community (Hammond, 2010; Williamson et al., 2018). These negative attitudes and perceptions play a major role why psychological barriers continue to exist and contribute to disparities in organ donation in the AA community (Robinson et al., 2015; Williamson et al., 2017). Williamson et al., (2017) used focus groups to evaluate AA attitudes and perceptions regarding organ donation, identifying mistrust as a major barrier to AA willingness to register as organ donors. Participants credited racism, favoritism towards white people during the donation process, and the belief AA organ donors who become ill will receive inferior medical care in order to harvest their organs for others, as key deterrent responsible for AA mistrust of the medical community and reluctance to become an organ donor. (Williamson et al., 2017). The participants credit the media for the increase in AA awareness regarding the seriousness and shortage of AA organ donors (Williamson et al., 2017). However, they also believe the media has contributed to the negative perceptions of the AA community through their less than favorable depiction of AAs on television. While negative depictions of AAs in the media do not formally translate into medical mistrust, it plays a powerful and significant role in shaping and perpetuating the negative stereotypes, myths, and perceptions of others. The study included primarily female participants and used focus groups. A more gender inclusive sample using individual interviews may provide results that are more generalizable and informative to the AA community.

The implications of this research can be life changing for those with debilitating illness and organ failure. However, because medical mistrust is a key determinant in AA organ donation decision-making, it is important to understand the lived experiences of AAs with mistrust to address the negative perceptions that prevent many AAs from becoming organ donors. New knowledge related to the behaviors, perceptions, and beliefs of AAs may aid in improving organ donation in the AA community.

There is an acute separation between AA health care decision-making and behavior. While the historical reasons for AAs to be distrustful and reluctant to become an organ donor are significant, there is a need for additional research to explore why medical mistrust continues to influence AA health related decision-making and behaviors. Understanding why medical mistrust is important to improving health behaviors and decision-making in the AA community is essential to implementing change in the negative perceptions that prevent many AAs from becoming organ donors (Arnett et al., 2016; Hammond, 2010; Robinson et al., 2015; Williamson et al., 2017).

Genuine understanding from health care practitioners can help repair the harm AAs experience from racism and discrimination. Improved understanding creates a dialogue within the medical community to discuss and search for answers to help heal past and present relationships damaged from ignorance and intolerance. This inquiry is dedicated to creating positive social change within the AA community to help improve the misconceptions, myths, and suspicions that exist within the AA population that contribute to their poor health care behaviors and decisions. This research can save lives and increase the quality of life in those AA patients who face life threatening disease and organ failure.

Problem Statement

AAs are a small percent of the United States population but represent the most need for organ transplants (Dubay et al., 2017; Quick et al., 2016; Robinson et al., 2015). The shortage of donor organs causes a disparity in the AA community because there are more individuals waiting for donor organs than organs available for transplant (Williams et al., 2017). Histocompatibility and a higher incidence of acute and chronic disease are key factors identified within the literature, which prevent AAs from becoming organ donors (Quick et al., 2016; Robinson et al., 2015; Williamson et al., 2017). A major barrier to organ donation in the AA community is their negative perceptions of the medical community (Robinson et al., 2015; Williamson et al., 2017). The Tuskegee Study and past unethical medical/research practices AAs have been subjected to have created a culture of mistrust within this community, negatively influencing their willingness to become an organ donor (Williams et al., 2017; Williamson et al., 2018).

The psychological definition of trust is a collection of learned experiences and expectations that cause an individual to have a favorable opinion or belief in the intentions and motives of others (Hammond, 2010). Mistrust is a collection of negative experiences that have resulted in negative perceptions, suspicion, and the expectation of a negative outcome (Hammond, 2010). Medical mistrust is the lack of trust or to have no confidence in the motives or intentions of a health care practitioner or organization (Hammond, 2010; Kinlock et al., 2017; Smirnoff et al., 2018).

While legislation and safeguards put into place to ensure ethical and humane medical practices to protect those willing to donate, AAs continue to be reluctant and suspicious. Even more distressing is their unwillingness to put aside their negative perceptions to improve the quality of life of their community. The intention of this study is to understand the lived experience of the AA, exploring the role of medical mistrust in their organ donation decisions. The implications of this research can be life changing for AAs with debilitating illness and organ failure.

It is imperative to address the disparities and barriers influencing AA organ donation to prevent a continued decline in the health of this community. Higher incidence of chronic illness and disease increases the urgency for continued research to address this problem. However, because medical mistrust is a key determinant in AA organ donation decision-making, it is important to understand the lived experiences of AAs with mistrust to address the negative perceptions that prevent many AAs from becoming organ donors.

New knowledge related to the behaviors, perceptions, and beliefs of AAs may be used to design programs to address the negative perceptions of AA toward organ donation with the potential to improve organ donation in the AA community.

Purpose

The purpose of this phenomenological qualitative research study is to help to understand the lived experiences of AAs relating to the role of medical mistrust in their organ donation decisions. A qualitative methodology helps researchers to understand medical mistrust and why it continues to influence the medical decisions of the AA community (Ravitch & Carl, 2016). Exploring the role and influence of medical mistrust in AA organ donation decisions has the potential to guide healthcare professionals and healthcare agencies in the development of policies and practices that may result in a more positive perception of organ donation in this community.

Research Question

What are the lived experiences of AAs relating to the role of medical mistrust in their organ donation decisions?

Theoretical Framework

Social cognitive theory (SCT) first began as a social learning theory (SLT) developed by Albert Bandura in the 1960s (Thojampa & Sarnkhaowkhom, 2019). SLT postulates that learning occurs from our direct observations and interaction with others (Thojampa & Sarnkhaowkhom, 2019). Bandura expanded his work in SLT in the 1980s to encompass the theory now known as SCT. In SCT, learning is a self-directed, shared collaboration between the individual and their environment (Dubay et al., 2017;

Thojampa & Sarnkhaowkhom, 2019). Knowledge is achieved through communication with others; the individual understands and uses the experiences of others to guide their actions and decisions (Dubay et al., 2017; Thojampa & Sarnkhaowkhom, 2019). Social communications can change an individual's perceptions either positively or negatively, influencing their motivation, intention, and behavior (Dubay et al., 2017; Robinson et al., 2015). Negative perceptions and experiences obtained from direct/indirect knowledge and through personal interactions with their community can alter an individual's perception and create doubt in the intentions and motivations of others, for what the individual perceives or learns as truth, influences their behavior (Dubay et al., 2017; Thojampa & Sarnkhaowkhom, 2019).

Nature of the Study

A qualitative phenomenological approach was used to gain an understanding of the participants' lived experiences regarding medical mistrust in their health care and organ donation decisions (Ravitch & Carl, 2016). A descriptive phenomenological approach focuses on the lived experience in the eyes of the participant, in the way they have experienced the phenomena (Ravitch & Carl, 2016). Using interviews to investigate AA beliefs and lived experiences allowed me to understand the role of medical mistrust in their health care and organ donation decisions. A genuine understanding of the phenomenon of medical mistrust is imperative to influencing healthcare providers to develop programs that have the potential to dispel mistrust and negative attitudes that prevent many AAs to become organ donors (Dubay et al., 2017; Hammond, 2010; Robinson et al., 2015).

Data analysis is extremely important to qualitative research because the results cannot be interpreted by themselves; it involves the researcher to perform a systematic, deliberate, and purposeful analysis of how the data is organized, managed, and interpreted (Ravitch & Carl, 2016). Using a phenomenological approach, I focused on the lived experience of the AA, to further investigate and define the concept and essential meanings of medical mistrust. Focusing on the AA’s personal lived experience with medical mistrust can determine its influence, if any, on their willingness to become an organ donor. Each participant experience was analyzed by identifying overlapping and redundant themes and descriptions (Ravitch & Carl, 2016). I used qualitative data analysis software to assist with transcription and textual interpretation to improve research validity and credibility (Ravitch & Carl, 2016).

Definitions

The definitions of the following key concepts are presented.

Health disparities are preventable differences in the social, economic, and environment of an individual or population that adversely affect and prevent the person or group of people from attaining optimal health, wellness, and economic opportunity (ODPHP, 2020).

Living organ donors are a group of individuals usually consisting of living family members or close friends who choose to donate their organs (HRSA, 2020). Living donors can donate the following organs: one out of their two kidneys, one or two lobes of their liver, tissue, or part of a lung, pancreas, and intestine (HRSA, 2020).

Medial mistrust has been defined as the lack of trust in the motives of a health care practitioner, organization, and effectiveness of the treatments (Hammond, 2010; Kinlock et al., 2017; Smirnoff et al., 2018).

Organ donation is the procedure involving the surgical removal of an organ or tissue from one person (the organ donor) to be transplanted into another (the recipient) (Health Resource & Services Administration (HRSA), 2020).

Organ donors are individuals (alive or deceased) who undergo the surgical removal of an organ or tissue from their body to be surgically transplanted into the body of another (HRSA,2020).

Posthumous organ donors are deceased individuals who choose to donate their organs upon medically confirmed brain death to a recipient waiting for transplant (HRSA, 2020).

Assumptions

It is assumed this research inquiry will elicit a positive change in the attitudes and perceptions of AAs regarding their mistrust of the medical community, resulting in an increase in organ donation within this community. It is also assumed that the sample chosen will be a fair representation on the AA community (Simon, 2011). A major assumption of this research suggests the study participants will not be suspicious or fearful of the intentions of the researcher and will answer the questions open and honestly when presented, detailed to their lived experience (Simon, 2011).

Scope and Delimitations

There is a dire need for continued research in AA organ donation. The demand for donor organs far surpasses the availability of organs for AAs awaiting organ transplant. The shortages in organs and organ donors are limited while, the numbers of AAs waiting for transplant rises, resulting in the upsurge of negative health outcomes and disparities within this community. Despite growing campaigns to educate and increase awareness in the AA population, this community continues to be reluctant and resistant to consider organ donation.

According to the literature, medical mistrust continues to be a primary determinant in AA reluctance to become an organ donor. The study's focus will address the personal lived experience of AAs with medical mistrust and investigate why it continues to have a destructive role in AA attitudes and beliefs. As the ethnicity most affected by disease and organ failure, their continued reluctance and unwillingness to participate organ donation has left the AA community exposed and vulnerable to critical illness and poor health outcomes.

Due to the low rates of organ donation in the AA community, it is determined the boundaries of the study be limited to the AA population to address personal experience with medical mistrust and its connection with their unwillingness to become an organ donor. The potential for transferability may be limited to the AA community because medical mistrust is a major reason for their reluctance to become an organ donor. Whereas other ethnicities have low rates of organ donation, their reasons for why their numbers are low may be different from AAs, resulting in the possibility of the study being untransferable.

Limitations

The challenges to this study include securing a non-threatening environment to interview the participants, ethnic and professional bias, the recruitment of appropriate study participants and my inexperience as a researcher and interviewer. It is important to secure an atmosphere that is private and non-threatening to encourage communication and allow for a free exchange of vital information among the participant and researcher. As a member of the same ethnic group being studied and health care professional, it was anticipated I may experience some bias, due to the sense of urgency and passion for the topic of study (Ravitch & Carl, 2016). A level of subjectivity is necessary for qualitative research; however, as an insider and researcher some degree of objectivity is required to gather, process, and examine data results (Ravitch & Carl, 2016) effectively and efficiently. As the researcher and nurse for this inquiry, it has taken a concentrated effort not to form opinions and bias regarding the importance of organ donation. I have employed the use of journaling to record and reflect upon any perceptions that may hinder my ability to recognize bias during the collection and interpretation of the study's data. These options were used to decrease researcher reflexivity and prejudice. Being aware of the influence a researcher can have on participant response makes it essential to design interview questions that are clear and concise, employing data analysis software to identify and organize reoccurring themes to compile data results to increase the study's credibility and rigor (Roller, 2017).

Significance

Understanding the factors that contribute to medical mistrust is essential to providing healthcare professionals with the information they need to develop strategies to guide programs, to assist in transforming the negative perceptions that prevent AAs from becoming organ donors. This study has the potential to elicit positive social change for three groups of stakeholders, the AA community, health professions, and society. The results of the study are an important first step towards creating a conversation within the healthcare community to develop awareness, understanding, and guide their search for solutions to improve organ donation in the AA community. The results of this study can provide information that will help healthcare professionals to develop programs to address the fears and concerns of the AA community regarding organ donation. Creating programs to address the fears and concerns of the AA community have the potential to increase their trust of the Healthcare system and their willingness to become organ donors. An increase in AA donors will decrease the burden on society to seek additional donors from other ethnic groups. The implications of this research have the potential to save lives and improve the quality of life in AA patients who suffer from life threatening disease and organ failure.

Summary

There is an urgent need for organ donors and organ donations in the AA community. The low incidence of AAs willing to become organ donors and shortages of transplantable organs available for AAs awaiting transplant will eventually result in catastrophic health outcomes in this community. Despite the research guidelines that govern and control unfair and unethical practices and increased awareness addressing the dire shortages of AAs willing to become organ donors and scarcity of organs available to AA patients waiting for transplants, there continues to be low rates of organ donations in the AA community.

Current negative perceptions and unwillingness to become an organ donor are the result of an undesirable and damaging history (Arnett et al., 2016; Dubay et al., 2017; Quick et. al., 2016; Robinson et al., 2015; Williamson et al., 2017). As a result of the pervasive negative beliefs and attitudes within the AA community, they are reluctant to consider becoming organ donors. However, to truly understand the nature of how medical mistrust translates in the AA community the concept must be explored. This study used qualitative interviews provide a deeper understanding of AA lived experience with the phenomenon of medical mistrust and how it relates to their continued unwillingness to become an organ donor.

SCT was used as the theoretical framework to gain a deeper understanding into AA personal lived experiences. SCT proposes that the individual learns from those within their environment through direct interaction or observation. Therefore, it is safe to assume that AA gain and exchange new knowledge from both their own personal experience and the experiences of others (Robinson et. al., 2015; Thojampa & Sarnkhaowkhom, 2019). The AA lived experience with medical mistrust can be a result of both personal and acquired lived experiences of others. While not all AAs may have experienced negative interactions with the medical community, information is exchanged among other AAs who have experienced mistreatment from the medical community. The past indiscretions of the medical community and a long and difficult history of mistreatment during slavery have caused many AA people to become suspicious of the intentions of the medical community. According to SCT, the negative social exchanges between AA members regarding the medical community can be a significant factor in their continued unwillingness to donate.

Chapter 2: Literature Review

AAs comprise 29% of the patients in the United States waiting for a life-saving organ transplant (OMH, 2016). There are more AA patients needing organ transplants than there are organs available for transplant and AAs willing to be become organ donors (Robinson et al., 2015; Williamson et al., 2017). The need for more organ donors has become imperative to improving health disparities and increasing the health and well-being of the AA community. Organ donation is a critical medical intervention for many AA patients suffering from acute and chronic organ failure. Increasing organ donors in the AA community would increase the availability of donor organs that are more closely crossed-matched and compatible with AA patients. Allowing more AAs, the opportunity to receive life-saving organ transplants to improve their quality of life.

Medical mistrust is an important determinant of AA reluctance to become an organ donor (Arnett, et al., 2016; Kinlock et al., 2017; Morgan et al., 2015; Quick et al., 2016; Williamson et al., 2017; Williamson et al., 2018). The purpose of this research is to explore AAs lived experiences with medical mistrust to determine why it continues to be a dominant, negative perception in the AA community, preventing many from giving and receiving the life-saving medical treatment to improve their quantity and quality of life. In Chapter 2, I describe the literature research strategies, the theoretical framework, and the contents of the review.

Literature Search Strategy

To identify prospective, peer-reviewed articles (as well as books and grey literature), the following electronic databases—CINAHL plus with full text, MEDLINE, ProQuest, and PUBMED —were searched for the years 2015 to 2020 using the following keywords: *AA, organ donation, mistrust, medical mistrust, distrust, kidney transplantation, organ transplants, barriers, organ donation,* and *health disparities*. A total of 49 articles were found at the beginning of the literature review search; however, many were over 5 years old. Many of the articles relevant to this research are outdated except for a few new publications recently found within the past 3 to 4 years. Research found within the past 5 years and older offer valuable insight and information relating to organ donation in the AA community.

Theoretical Foundation

Phenomenology is a philosophy and methodological framework in qualitative research that uses an individual's narrative account to explore and understand their reality and subjective lived experience within the phenomenon of study (Cilesiz, 2011; Lopez, & Willis, 2004). Phenomenology is the philosophy of experience, with several different philosophical approaches to understand and interpret human experience (Cilesiz, 2011). The philosophical approaches used in phenomenology are existential, hermeneutic, and transcendental, and it is important that the researcher identify the process that corresponds to the chosen philosophical approach used (Cilesiz, 2011; Lopez & Willis, 2004).

Existential phenomenology emphasizes the uniqueness of people as social beings looking at how they relate to others in their environment (Cilesiz, 2011). Existential phenomenology describes the participant experience as it is reflected in their ideals, intentions, and relationships (Cilesiz, 2011). This philosophy looks at the experiences and actions of the individual and not how they conform to a specific behavior (Cilesiz, 2011).

Unlike existential phenomenology, the hermeneutic philosophy of Heidegger is used to interpret the participants descriptions of their experience (Lopez & Willis, 2004). The hermeneutic approach uses both the opinions and perceptions of its participants and the researchers to interpret the participant's experience of the phenomenon in question (Lopez & Willis, 2004). The hermeneutic philosophy believes the perceptions of the researcher are just as important as the research participants and seeks to use both to interpret and construct meaning and understanding of the participants experience (Lopez & Willis, 2004).

Transcendental phenomenology uses a technique known as epoche or bracketing to obtain an unbiased description of the raw data (Cilesiz, 2011). Transcendental phenomenology is also known as descriptive phenomenology; the researcher does not interpret the data obtained but describes the data just as it was experienced (Lopez & Willis, 2004). The transcendental descriptive approach recognizes that an individual's subjective perception regarding their unique experience with a phenomenon, has value and merit in understanding what motivates them, because motivation influences behavior (Lopez & Willis, 2004). I chose a descriptive transcendental phenomenological approach because I wanted to obtain real and meaningful data describing the AA experience with medical mistrust to explore its influence on their organ donation decisions. I practiced the simple act of reserving my personal judgement (bracketing) so I can focus on the study participants' actual lived experience with the phenomenon of inquiry (Cilesiz, 2011). I described my participants' experience verbatim just as they have described and experienced it. The only way to truly provide a realistic account of the AA lived experience was to describe their real, lived experience with data that is pure and free from researcher opinions and bias.

SCT is a social learning theory developed by Albert Bandura in 1986 (Thojampa & Sarnkhaowkhom, 2019). He defined "learning" as a lasting change in human behavior based on an individual's direct or indirect contact with their environment (Thojampa & Sarnkhaowkhom, 2019). In SCT, individual behavior is influenced by personal experience. To change or alter individual behavior, individuals must first change their perception of their experience that resulted in the behavior. As a major determinant of human behavior and development, SCT is an extremely influential and used in many areas of education and social research (Thojampa & Sarnkhaowkhom, 2019). SCT relies on the individual's ability to reason, which is key to understanding, predicting, and changing behavior (Thojampa & Sarnkhaowkhom, 2019). SCT is used to understand how individuals think and view their social experiences. As a result of their personal experience, it is possible these experiences can often influence their intentions and behavior.

According to Thojampa and Sarnkhaowkhom (2019), an assumption of SCT is that people learn behaviors and concepts through observing the behavior of those around them. Learning is an internal cognitive process that may not result in a behavior change. While individuals acquire knowledge in the learning process, they may not always choose to change their behavior. Cognition plays an active role in learning; as the individual gains knowledge and understanding, they reflect upon their experience and make a choice whether to engage or not in a specific behavior. Behavior is an individual's response to their environment. AA perceptions are based on knowledge of past and current adverse experiences of others and can negatively affect their response and behavior. According to SCT, individuals are socialized within the group in which they are a member, readily acquiring the group's norms, knowledge, and perceptions (Thojampa & Sarnkhaowkhom, 2019).

Dubay et al. (2017) used SCT to develop and create research questions to identify what factors influence AAs to become organ donors. Their findings were consistent with SCT: behavior is determined by the individual and their environment and plays a central role in an AA's decision to donate an organ. The participants were confident in their understanding of organ donation and their ability to make their own decisions based on the information given to them. The study's findings revealed that AAs who choose to become organ donors were motivated by knowing a family member or friend who needed a transplant or was a transplant recipient (Dubay et. al., 2017).

Thojampa and Sarnkhaowkhom (2019) recognized that behavioral changes in the individual are dependent upon their environment. The study focused on those with diabetes and explores how their environment can impact their health care decisions and behaviors. The assumptions of SCT are significant to the study because they illustrate how social interactions, health, and self-efficacy play an integral role in changing undesirable behaviors in the diabetic patient.

Joseph et al. (2017) used SCT to promote exercise and increase physical activity in AA women. SCT is pertinent to this study because its premise postulates that the individual's beliefs, attitudes and social and/or physical environment work together to encourage behavior. Thojampa and Sarnkhaowkhom (2019) suggested theory-based behavioral strategies, much like those used in SCT, could benefit the AA community by promoting positive health behaviors.

SCT is the theoretical framework of my research inquiry because its premise fully represents how AAs have internalized their experience and knowledge of medical mistrust, which then influences their past and present organ donation decisions and behaviors. The research question explored AAs' medical mistrust and why it continues to be prevalent in AA decision-making. Current cynical perceptions and behaviors are the result of AAs' past and current negative perceptions of society, government, and the medical community. AAs view these institutions as unreceptive to AAs' concerns or needs, which results in their reluctance to become an organ donor (Hammond, 2010).

Literature Review: Key Variables

Organ donation is an important, life-altering medical intervention that represents the only option for many AAs in organ failure to survive, thrive, and live a good quality of life (Williamson et al., 2017). AA organ donation decisions and behavior are influenced by a variety of factors. The need for organ donation is critical in the AA community and the need for organ transplants surpasses the numbers of AAs willing to become organ donors (Robinson et al., 2015; Williamson et al., 2017). AAs are disproportionately impacted by chronic and acute health conditions that can result in organ failure (Robinson et al., 2015; Williamson et al., 2017; Williamson et al., 2018). Medical mistrust is a major determinant influencing AAs willingness to become organ donors (Arnett, et al., 2016; Kinlock et al., 2017; Morgan et al., 2015; Quick et al., 2016; Williamson et al., 2017; Williamson et al., 2018). The unwillingness of AAs to become organ donors creates a severe health disparity in the Black community, sometimes resulting in death for those AAs waiting to receive on organ transplant (Williams et al., 2017). Histocompatibility and tissue-typing specific to people of color makes it difficult to secure well matched transplant organs, and it more imperative to increase organ donation in the AA community (Robinson & Arriola, 2015; Robinson, et al., 2015; Williamson et al., 2017). Lastly, a long history of medical mistreatment and slavery has predisposed the AA to a highly adverse perception of organ donation and has not been helpful in persuading AAs to become organ donors (Robinson et al., 2015; Williamson, et al., 2017; Williamson et al., 2018).

Critical Need for AA Organ Donors

The need for transplantable organs in the AA community far exceeds the demand (Robinson et al., 2015; Williamson et al., 2017). AAs represent 29% of the organ donors on the current United States transplant registry but account for only thirteen percent of the organ donors (U.S Department of Health and Human Services Office of Minority Health [OMH], 2016). AAs are disproportionately affected by the shortage of donor organs available for transplant and this gap continues to grow (Robinson & Arriola, 2015; Robinson et al., 2015; Williamson et al., 2017).

In Illinois, where this study was conducted, AA recruitment for organ donation is more successful than other states with over 6.5 million participants, and with AA representing over half of registered Illinois organ donors (Illinois Organ and Tissue Donation; Secretary of State Jessie White, 2020). Even with the success of the Illinois registry, people of color living in Illinois still make up 60% of the patients in Illinois waiting for transplants (Illinois Organ and Tissue Donation. Secretary of State Jessie White, 2020). Every 10 minutes, someone is placed on the Illinois transplant list, with kidneys as the most requested of all the transplants (Illinois Organ and Tissue Donation; Secretary of State Jessie White, 2020). Currently, there are 3,328 people waiting for a kidney transplant in Illinois, and 229 waiting for heart transplants (Gift of Hope, 2020).

Health Disparities Impacting African American Organ Donation

The increased incidence of acute and chronic illness in the AA community has both intensified the need for well-matched donor organs and decreased the numbers of AAs willing to donate due to pre-existing disease (Harding et al., 2017; Robinson et al., 2015; Williamson et al., 2017). AAs are disproportionately affected by a higher incidence of hypertension, diabetes, asthma, renal failure, and heart disease when compared to other races (Robinson & Arriola, 2015; Robinson et al., 2015; Williamson et al., 2017). When treatment options are not accessed due to inability, unavailability, or medical mistrust the consequence is a delay in treatment, increasing the financial burden on the healthcare system, eventually resulting in the need for a higher and more costly care (Arnett et al., 2016; Robinson et al., 2015; Williamson et al., 2017; Williamson et al., 2018). It increases the financial burden on the health care system eventually resulting in a higher level of care and a greater financial impact (Arnett et al., 2016). As a result of the higher incidence of disease, and a lowered access to health care and quality, AAs are three times more likely to experience end-stage renal failure than their White counterparts increasing their need for an organ transplant (Robinson & Arriola, 2015). Currently, 94% of the AAs on the transplant list are waiting for a kidney transplant as a result of the high incidence of health disparities and chronic illnesses that exist in the AA community (Robinson & Arriola, 2015; Robinson et al., 2015). Many AAs are waiting longer for organ transplants sometimes not receiving the opportunity for a chance at a better quality of life until it is too late (Almassi, 2014; Robinson et al., 2015).

Another factor contributing to the disparities in the organ donation process, is the shortage of donor organs available to AA patients because of the difficulty in finding well-matched organs (Robinson & Arriola, 2015; Robinson et. al., 2015; Williamson et al., 2017). Although it is normal to utilize donor organs procured from other races to provide AA patients transplants, they are not always as successful as organs obtained from people of the same ethnic group (Robinson & Arriola, 2015; Robinson et al., 2015; Williamson et al. 2017). AA organs that are procured and donated to other AA patients are more compatible (Robinson et al., 2015; Williamson et al. 2017). AAs in need of a kidney transplant must be closely matched to an organ with similar genetic makeup (Robinson et al., 2015). The transplant recipient and donor organ must be matched closely, with a similar complex protein human lymphocyte antigen (Robinson et al., 2015). To reduce organ rejection and ensure a successful transplant the donor organ should come from a person of the same race (Robinson et al., 2015).

Role of Medical Mistrust in AA Organ Donation

The past negative experiences of slavery and medical mistreatment of the AA is and continues to be, an unfavorable and painful narrative recited throughout the AA community for generations (Arnett, et al., 2016; Kinlock et al., 2017; Quick et al., 2016; Robinson et al., 2015; Williamson et al., 2017). According to Hammond (2010), when a person becomes distrustful in the intentions of another, it deepens their level of mistrust, creating a negative perception that causes doubt and disturbs their sense of psychological and physical safety. When a person's sense of safety is threatened, their perceptions are at risk to the negative influences around them, creating a sense of mistrust, leading to their anticipation of negative outcomes (Hammond, 2010; Williamson et al., 2018). Past experiences can shape perceptions and influence an individual's decisions and intention to participate or not to participate in a specific behavior (Dubay et al., 2017).

The build-up of negative interactions and reactions can lead AAs to expect negative outcomes (Hammond, 2010). The anticipation of these negative outcomes is what influences the negative social and psychological beliefs and attitudes that lead to the concept of medical mistrust (Hammond, 2010; Williamson et al., 2017). Medical mistrust has a direct relationship to past and present negative AA attitudes, expectations, and motives of the medical community (Hammond, 2010; Kinlock et al., 2017; Smirnoff et al.,2018). Medical mistrust is the direct result of unfavorable AA opinions and is related to the misconceptions, myths and suspicion that surround organ donation, impacting AA decisions, behavior, and willingness to become organ donors (Hammond, 2010; Kinlock et al., 2017; Smirnoff et al.,2018).

Role of the Health Care Professional in Organ Donation

Mistrust in health care organization and health care providers has disproportionately impacted the interpersonal relationships of the AA and their health care practitioners (HCP) (Cuevas, O'Brien & Saha, 2019). The history of mistrust within the AA community has negatively influenced patient – HCP relationships, reduced AA satisfaction with the care they receive in the health care system, low compliance with treatment, and resulted in the underutilization of health care services (Cuevas et al., 2019). The role of the health care provider is to encourage a more positive patient-centered interaction with the AA community to improve patient- HCP relationships and health outcomes (Cuevas et al., 2016). It is necessary to establish trust in the patient-provider interactions to reduce the historically negative attitudes AAs have of the medical profession that have influenced their perceptions of organ donation. It is imperative the HCPs incorporate patient needs and concerns into their plan of care to encourage a partnership built on trust, without bias or harmful stereo types to reach mutually agreed upon goals (Cuevas et al., 2019; King & Redwood, 2016; Cuevas et al., 2019). Patients who are included in their treatment are found to exhibit more positive attitudes of their HCPs and exhibit more affirmative health behaviors (Cuevas et al., 2019). An investigation into AA mistrust is necessary to dispel negative perceptions and provide HCPs with strategies to improve AA trust in the health care system (Cuevas et al., 2019). African American trust in the health care system is essential to improving organ donation rates in the AA community (Robinson et al., 2015).

Organ donation must become a priority in the AA community to decrease the health disparities facing the AA community and financial burden on society. The purpose of this research was to explore AA perceptions regarding organ donation. This information has the potential to identify new strategies that can be used to dispel negative AAs attitudes and beliefs, to improve organ donation rates in the AA community to provide more opportunities for AAs to receive a life-saving organ transplant (Robinson et al., 2015; Williamson et al., 2017).

Summary

Walden's electronic databases were used to access forty-nine peer-reviewed journal articles. Many of the articles accessed were 5 years or older but continued to be pertinent to this inquiry. This research will add knowledge and provide current research and understanding of AA experiences with medical mistrust and organ donation. In this study, SCT was used to understand AA experience with medical mistrust, to determine how this experience has influenced their perceptions and beliefs regarding organ donation.

Most of the research obtained for the literature review used a cross-sectional design to identify the variables that influence AA unwillingness to become an organ donor (Arnett, et al., 2016; Kinlock et al., 2017; Robinson et al., 2015; Williamson et al., 2017). The cross-sectional design limited the research studies because it failed to provide an in depth look at why AAs continue to have a negative perception of the medical community (Arnett, et al., 2016; Kinlock et al., 2017; Robinson et al., 2015; Williamson et al., 2017). Several studies used focus groups to explore AA perceptions regarding medical mistrust and organ donation. The use of focus group was instrumental in easing participant discomfort and encourage a more open discussion of sensitive topics (Cuevas et al., 2016; Williamson et al., 2017; Williamson et al., 2018). However, the focus group limited the researcher's search for an in depth, genuine, and meaningful exploration into the persistent negative perceptions AAs have of the medical community and how these perceptions can result in their reluctance to become an organ donor (Cuevas et al., 2016; Williamson et al., 2017; Williamson et al., 2018).

The disparities in AA organ donation are significant and required immediate intervention to improve the critical gaps in AA health care quality. Organ donation is an important medical intervention for AAs suffering from organ failure. For many, AAs, organ transplantation is critical to their continued survival. However, serious shortages of donor organs and AA resistance to organ donation has severely limited the availability of transplantable organs. A long history of ill-treatment and mistrust has resulted in the ill-feelings and negative perceptions responsible for AA unwillingness to become organ donors. To improve organ donation in the AA community, it is important to first understand the historical and societal foundations that have contributed to the mistrust of the medical community and how it has influenced AA reluctance to become organ donors. Not many studies investigate how medical mistrust impacts AA donation decisions. Therefore, the intention of this study is to understand the unique nature of AA mistrust, to affect a positive change in AA organ donation decision-making through understanding and compassion.

Chapter 3: Research Method

Introduction

The purpose of this phenomenological qualitative research study was to understand the lived experiences of AAs relating to the role of medical mistrust in their organ donation decisions. A qualitative approach provides an opportunity to gain an understanding of the concept of medical mistrust and its continued presence in the AA community (Ravitch & Carl, 2016). Exploring the role and influence of medical mistrust in AA organ donation decisions have the potential to guide healthcare professionals and healthcare agencies in the development of policies and practices that may result in a more positive perception of organ donation in this community**.** Chapter 3 will introduce the study's research design and rationale, role of the researcher, methodology, and issues of trustworthiness.

Research Design and Rationale

The primary question guiding this research is: What are the lived experiences of AAs relating to the role of medical mistrust in their organ donation decisions? There is an urgent need for more AAs to become organ donors. Critical shortages of organ donors in the AA community have increased the incidence of chronic illness and health disparities for this group. The literature acknowledged that medical mistrust plays a significant role in AA unwillingness to become organ donors. Medical mistrust is defined as a suspicion or a lack of confidence in the intentions of the medical community and is the direct result of a long nefarious history of medical and societal mistreatment in the AA community (Hammond, 2010; Kinlock et al., 2017; Smirnoff et al.,2018). Therefore, it is important to understand and define AA perceptions of what is meant by medical mistrust and explore its influence on the lived experiences, perceptions, and beliefs in AA organ donation.

A descriptive, transcendental, phenomenological design was used to provide an understanding of the lived experience, and perceptions, of AAs regarding medical mistrust and determine its role in their organ donation decisions. A quantitative design was not used in this study because it identifies relationships or causal factors among a study's variables and that is not the purpose of this study (Gray et al., 2017). The primary objective of this study was to seek knowledge and meaning through the lived experience of the participants, which can only be investigated through a qualitative, transcendental, phenomenological descriptive design (Phillips - Pula et al., 2011). A qualitative researcher uses observations, journaling, and interviews to gather data through language, using text-based analysis to offer an in depth and richer understanding of the human experience (Burkholder et al., 2016*)*. It was important to gain a deeper understanding of why AAs are unwilling to donate, and the phenomenological approach is the best design and method to identify and understand those perceptions that prevent AAs from becoming organ donors.

Role of the Researcher

The role of the researcher in qualitative phenomenological study is to collect, organize, and analyze the lived experiences of those who have experienced a phenomenon (Burkholder et al., 2016). In qualitative research, the researcher is the instrument (Burkholder et al., 2016). The researcher's goal is to understand human interaction with a phenomenon to identify the perceptions and feelings of those experiencing the event (Burkholder et al., 2016). As a novice researcher, nurse, and member of the AA community, it is imperative this study remains free from my personal opinions and beliefs to prevent bias. To gain a genuine understanding of the lived experiences of AAs, I must be careful to not lead the study participants or push them to answer questions (Burkholder et al., 2016). To understand the personal lived experience of the AA participants, it is vital to not share my experiences as a member of the AA community, nurse, and researcher, or guide their answers in anyway. To prevent bias in this study, participant interviews were be recorded and transcribed per verbatim, and a reflective journal was used to record researcher feelings and ideas (Burkholder et al., 2016). Bracketing was also used throughout the study to identify and acknowledge my own feelings and experiences to allow the participants to be free without bias or researcher assistance to express their personal experiences and perceptions of the phenomenon being studied.

Methodology

Phenomenological Methodology

Phenomenology is a method that allows the researcher to explore and describe meaning in the personal lived experience of an individual with a phenomenon, to search for a deeper understanding or meaning of a phenomenon (Cilesiz, 2011). Phenomenology was a perfect fit for my study because it allowed me to investigate the lived experience of others, to offer a first-hand account of their own personal experience with the phenomenon under scrutiny. Phenomenology also helped to develop a deeper understanding of the experience others have had with the phenomenon of study (Cilesiz, 2011). The phenomenological method was appropriate to give the AA community a voice and provide understanding of their experiences relating to the role of medical mistrust and its influence in their organ donation decisions.

Using a descriptive phenomenological, approach in my data collection and analysis, I collected my data through the use of a semi-structured interview and transcribed my participants responses and perceptions in the same way in which they have experienced them. According to Phillips - Pula et al., (2011), understanding of the participants' experience in the same way they experienced it helped me to understand the true nature of their experience with the phenomenon. I refrained from making personal judgements and focused completely on the interview process to make sure my own personal bias did not interfere with my ability to provide rich thick descriptions of my participants experience (Phillips - Pula et al., 2011).

Study Participants

The population under study included AA male and females 18 years of age and older who were able to read and write English. This population of participants was chosen because many within the AA community are least likely to become organ donors but represent the highest need for organ donation making it is important to understand the reasons why they are reluctant to donate through their perspective and lived experiences.

Sampling Strategy

In this study, a purposeful sampling strategy was employed to select participants within the AA population. Purposeful sampling aligns with the phenomenological method and design of this study (Burkholder et al., 2016). Purposeful sampling allowed me to select participants based on their specific characteristics to enhance the trustworthiness and reliability of the study (Houser, 2015). This sampling strategy is based on certain criteria and helps researchers to select the most appropriate participants to provide the rich and meaningful data required to investigate the phenomenon under study (Burkholder et al., 2016; Cilesiz, 2011).

Purposeful sampling provides detailed knowledge and perceptions of a specific population selected for their unique ability to answer a research question (Burkholder et al., 2016). This inquiry deliberately selected AA participants because of their unique experience with the phenomenon under study. Through their perspective, I have acquired knowledge to understand the reasons why they are unwilling to become organ donors. Investigating their experiences with medical mistrust allowed me to identify the extent to which this phenomenon continues to influence organ donation rates in the AA community. Snowball sampling further helped to implement a referral process to aid in the recruitment of appropriate participants for this inquiry (Houser, 2015).

Other considerations regarding sample selection and size in phenomenology include the aim of phenomenology is not to find generalizability in the research findings but to obtain descriptions of the lived experience of the participant and not the population as a whole (Cilesiz, 2011). Phenomenology requires a sample to be homogenous to effectively describe a shared experience among a group of participants. A heterogenous group would be inappropriate and prevent me from obtaining data strictly from those in the AA community (Cilesiz, 2011).

Participant Selection Criteria

Criterion sampling helps to inform the research study by selecting participants that match a prearranged set of characteristics and meet both the study's inclusion and exclusion criteria (Houser, 2015; Rudestam & Newton, 2015). Houser (2015) reported that inclusion criteria limits bias by objectively identifying the criteria and those subjects most appropriate to participate in the study; exclusion criteria are characteristics that prevent a subject from participating in a study. He further reports that some participants are not suitable to participate in the study and must be excluded to prevent the accumulation of unnecessary data. The following inclusion and exclusion criteria were employed when selecting this study's participants.

Inclusion Criteria

- African American Male and Females
- Over 18 years of age
- Read and write English

Exclusion Criteria

- Participants with English proficiency difficulties
- Transplant recipients

Sample Size

According to Burkholder et al. (2016), using a sample size between five and 15 participants is appropriate for a phenomenological study. For this study, I wanted to recruit six to 10 participants to gain a meaningful and in-depth understanding of the AA lived experience with medical mistrust and its role in AA organ donation. Additional participants were recruited as needed, until saturation is achieved. According to Gray et al. (2017), in qualitative research, the sample size is determined by saturation. To achieve saturation, the quality and depth of the information received from the study's participants must be significant to gain insight into a phenomenon, concept, or an event. The researcher must be careful to ensure that the sample size is not too small, because a sample too small can affect the quality of information obtained and reduce the credibility of the research results (Gray et al., 2017). An appropriate sample size is determined when saturation is achieved, and no new themes or categories are found (Gray et al., 2017). Saturation occurs when themes are repeated, and no new information is obtained (Gray et al., 2017).

Procedure for Recruitment and Data Collection

After obtaining Walden University IRB approval, I recruited participants using a recruitment flyer (see Appendix A), through social media accounts set up and accessed solely by myself, the researcher. Using Facebook, Twitter, LinkedIn, and Walden's participant pool, recruitment postings were placed on these forums to inform participants of the research study, its purpose, requirements for participation, with my contact information. In addition to the social media recruitment strategies, I have also elicited permission from the neighborhood churches to post flyers on their church bulletin boards to recruit participants. Flyers contained the same information as the social media postings informing the participants of the research study's purpose, requirements for participation, and my contact information. The flyer informs the individuals that if they are interested in learning more about the study, to contact me. In addition, I added a statement to the flyer requesting that participants share the flyer with other individuals who they believe might be interested in learning more about this study.

Individuals who contacted me were screened (see Appendix B) to determine if they meet the inclusion criteria. I thanked those whose who do not meet the inclusion criteria for their interest in the study. For those who did meet the inclusion criteria, I reviewed the study's purpose and expectations, the voluntary nature of participation, and confirmed confidentiality will be provided. I emailed the informed consent to those who agree to participate in the study and asked them to return the signed copy by email. After receiving the participants informed signed consent, I scheduled a telephone interview with them within a 1 to 2-week period after they returned the consent. After the informed consent was completed and signed, I emailed each participant a demographic questionnaire that includes information about their race, gender, organ donation status and if they have a living will. I asked them to complete and return the questionnaire to me before our scheduled interview date.

Living wills are one in four types of advanced directives that allows patients to voice their wishes in the event they experience terminal illness (Illinois Department of Public Health [IDPH], 2020). The purpose of a living will ensure a participant's medical or end of life wishes are followed if they became unable to communicate their needs due to illness (Illinois Department of Public Health [IDPH], 2020). Participants with living wills understand the importance of designating someone to follow their wishes, to ensure they have a voice in what happens to them in the event they are too ill and unable to speak for themselves (Illinois Department of Public Health [IDPH], 2020). Living wills are essential to organ donation because they allow the participant to clearly communicate their final wishes regarding organ donation and takes the responsibility of making these difficult decisions from of their family (Illinois Department of Public Health [IDPH], 2020).

For each telephone interview, the participant was encouraged to choose a private place where their conversations could not be heard and there was less likelihood of distractions. The participants were notified that their participation in this study was strictly voluntary, posing no threat, with their confidentiality protected. Participants were reminded of their rights as participants in a research study.

Interview Procedure

Before each interview, I reminded each participant that the interview would be audio taped to ensure the accuracy of the data obtained. The interviews lasted 45 to 60 minutes and began with a brief introduction and greeting to each participant thanking them for their agreement to participate in the study (see Interview Protocol Appendix C). Slowly, the essential and sensitive research questions were introduced to each research subject to obtain data and focus of the study. The consent, demographic questionnaire, interview recording, and transcription were assigned a pseudonym, e.g., Participant 1, 2, etc. After the completion of each interview, there was a brief closing statement and a chance for each participant to ask questions. The subjects were informed of their opportunity to request and receive copies of their interview transcripts if they so desire, to permit them to check for accuracy before the study’s conclusion.

Open-ended semi-structured interviews are used in phenomenology. Questions that are structured properly aid the researcher the opportunity to gather data and avoid influencing their participants response (Cilesiz, 2011). All data were obtained through interviews and researcher observations. Interview question asked the participants to describe their experience in their own words and allow participants to give feedback to ensure transcription accuracy. Participant reflection and feedback is important to the phenomenological interview, and when used with bracketing, it helped to decreased bias and clarify participant responses (Cilesiz, 2011).

Instrumentation

Open-ended guiding questions were used to uncover the lived experiences of AAs relating to the role of medical mistrust in their organ donation decisions. According to Rubin and Rubin (2012), interview questions must be clear, concise, open-ended, in easy to understand language and follow an interview protocol approved by IRB (See Appendix C). In addition, participants were asked the same questions to simplify data analysis and increase validity and meaningfulness of the study’s data. Using follow up questions and prompts allowed participants to provide detail and an in-depth understanding of their experience. The objective of the interview process was to explore and uncover the lived experience of AAs with medical mistrust and its role in their organ donation decisions.

Data was collected using telephone interviews. The interviews were recorded using a digital MP3 device. I took take field notes to record participant non-verbal cues and observations. According to Ravitch and Carl (2016), observation and field notes are especially important to qualitative research because they allow the researcher to document their observations, the interview environment, and record the participants actions presented through nonverbal cues. Field notes also allowed me to reflect and identify my own personal preconceptions and assumptions to decrease bias in study data.

Interviews were scheduled for an hour with one interview per day to guarantee my precision with data interpretation and analysis and prevent participant fatigue. All interviews were conducted over the phone, in a quiet, confidential setting of the participants' choosing. All interviews are conducted with respect and compassion for the comfort and well-being of each participant. Each participant was given the option to withdraw from the interview or study at any time. Data collected, audiotapes, written notes journals, and signed consents will remain confidential and stored in a locked area to protect participant privacy.

Interview Questions

The guiding research question was "What are the lived experiences of AAs relating to the role of medical mistrust in their organ donation decisions?" The following guiding questions were developed from my review of the literature to generate data to obtain responses related to the guiding research question. The questions reveal trends found within the literature and reflect concepts established by my theoretical framework (Smirnoff et al.,2018; Williamson et al., 2017). Both the literature and the theoretical framework were used to develop my guiding questions. Prompts and follow up questions were used to clarify and or provide depth to the participants responses.

The following guiding questions explored AA perceptions of the medical community to determine if their experience has impacted their organ donation decisions.

Asking the participant to describe their individual experiences with the medical community and organ donation allowed me to gain insight, into why AAs are mistrustful of the medical community and how these perceptions may have been influenced by their environment and interactions with other AAs (DuBay et al., 2017; Hammond, 2010; Joseph et al., 2017). As result, it is most likely that AAs have internalized their knowledge of the unfavorable experiences and perceptions of others in their community, resulting in continued mistrust of the healthcare system and negative views regarding organ donation (DuBay et al., 2017; Hammond, 2010).

Guiding Questions

1. Tell me about your experience as it relates to the care you have received from your medical provider?
2. Can you describe any experience with a health care professional that may have influenced your perception of the medical community?
3. Describe any experience where you believe you received a lower quality of care because you are AA?
4. Can you describe any experience that has positively influenced your beliefs regarding organ donation?
5. Can you describe any experience that has negatively influenced your beliefs regarding organ donation?
6. What do you believe could be done to increase organ donation in the AA community?

Data Analysis

It is important to be intentional and transparent in the research process (Ravitch & Carl, 2016). To be intentional involves the researcher being present in the subjects lived experience, identifying essential meanings and themes to further the knowledge of the phenomenon (Phillips- Pula et al., 2011). Transparency aids in establishing consistency and strength in the data results; it is important the researcher can explain their research methods and process in analyzing data and interpreting the results (Ravitch & Carl, 2016).

Clark Moustakas, a student of Edmund Husserl, developed the transcendental phenomenological approach to data collection and analysis as a method to understand and describe each participant’s experience exactly as it was lived and communicated by the participant (Burkholder et al., 2016; Patton, 2016; Phillips- Pula et al., 2011). Moustakas approach to phenomenological data analysis uses the participants actual described experiences because these cannot be changed by the researcher without losing their meaning (Phillips- Pula et al.,2011; Ravitch & Carl, 2016). The researcher analyzing the participant’s lived experience must not allow bias to dominate their descriptions of the phenomenon (Phillips- Pula et al., 2011). Researchers should be self-reflective during the entire research process to ensure the trustworthiness and validity of the data analysis and collection (Ravitch & Carl, 2016).

Using the Moustakas approach, known in the literature as descriptive phenomenology I used a Husserlian philosophy. This philosophy and methodology were used to focus on the creation of knowledge through exploration of the participants experience with a phenomenon. Unlike the Heideggerian philosophy which goes beyond an in-depth description to also interpret the subjects experience and the researcher's perception regarding their experience (Matua & Van Der Wal, 2014). I read through and manually transcribed each interview verbatim to reduce any bias and maintain the study's rigor. I collected and reported the participant's lived experiences as simple text. I read and compared the transcribed data to ensure accuracy in the transcription process. After accuracy is confirmed, the data was coded using the participants actual words and divided into common themes and patterns using Nvivo Qualitative Data Analysis (QDA) software to help analyze, code, organize and store the study's data.

I focused on the central meanings of the participant's experience to provide rich in-depth descriptions and find common themes, categories, and patterns to identify and organize data for analysis (Burkholder et al., 2016; Phillips- Pula et al., 2011). In the tradition of transcendental phenomenology, information was divided into groups of short words and/or phrases that captured the data's meaning to ensure a more straightforward and simplistic analytical process (Ravitch & Carl, 2016; Saldana, 2016). Once the data was coded, and over lapping and redundant statements were identified, the common participant responses were grouped into categories and themes to aid in providing answers to the guiding research question.

Discrepant cases in qualitative research often contradict the common theme or categories uncovered in the study's data (Ravitch & Carl, 2016). To deal with possible discrepant cases during data collection it may be necessary for me to encourage future participants to further elaborate on their answers to see if there is collaboration for the discrepant case (Rudestam & Newton, 2015). Credibility can be established when data can be verified through multiple data sources. According to Rudestam and Newton (2015), the use of triangulation is helpful in reevaluating a study's discrepant data.

Issues of Trustworthiness

To establish if a study's research is trustworthy it must be credible, transferable, dependable, and confirmable (Patton, 2015). A study is trustworthy when its arguments and/or research questions are supported with sound reasoning and abundant evidence to support its conclusions (Patton, 2015). Trustworthiness is a method or process, which qualitative researchers use to validate the quality and strength of their research (Ravitch & Carl, 2016). Trustworthiness in qualitative research indicates that the research is authentic and confirms the study's findings accurately reflect the participants' lived experience of the phenomenon in question (Ravitch & Carl, 2016).

Credibility

Credibility is one of four criteria for establishing the trustworthiness of a qualitative study. For a study to be considered credible, the study's findings must be believable, have strong evidence, a sound argument, and strong data to confirm the study's findings (Patton, 2015). Credibility is the process in which the researcher as the instrument investigates and analyzes the data, to find genuine meaning from all the findings, including those from discrepant case which allows for alternative confirmation of the research questions (Ravitch & Carl, 2016). Credibility is related to the research methods and design, with the goal of credibility being achieved through the process of triangulation (Ravitch & Carl, 2016). Triangulation is a research approach used to determining a study's trustworthiness and credibility. Triangulation uses information obtained from multiple data sources during the data collection and coding process to maintain research alignment and credibility (Ravitch & Carl, 2016). Confidence in a study's credibility is supported by the participants' acknowledgement of their responses, the strength and analysis of the data obtained through multiple sources, independent data interpretations, control of negative influences, and a sound theoretical model (Patton, 2015; Ravitch & Carl, 2016).

I used data triangulation by comparing the information obtained from my study's interviews, observations, field notes, and journals to determine credibility of the findings. In addition, I allowed the participants to review their interview transcripts to ensure accuracy of the information transcribed. I practiced self-reflection and used journals to have ongoing assessment of my personal opinions and not allow any possible bias to influence the research process to assure trustworthiness and credibility in my data analysis and collection (Ravitch & Carl, 2016).

Transferability

Transferability provides evidence that the research study's findings could be applicable to other situations and populations (Creswell & Creswell, 2018). While the researcher cannot assure that the research study's findings are applicable, they can provide evidence that applicability is likely (Creswell & Creswell, 2018). Transferability can only be accomplished if the researcher obtained insightful, genuine descriptions and purposeful sampling (Creswell & Creswell, 2018). Thick descriptions provided a vigorous and meticulous account of participant experiences during data collection and helped me to associate and connect the cultural and social circumstances surrounding the data collection. For example, acknowledging the environment where the interviews occurred helped to reconstruct the participant interview and provide a richer and fuller understanding of the participant's experience. Understanding participant perceptions and how their own personal biases may affect their responses, helped me to connect social and cultural implications that frame my research, and help other researchers to make transferability judgements for themselves.

Qualitative phenomenological research methods were used to investigate the lived experiences of AAs; however, this study may be transferable to other minority populations that have low organ donation rates. The sample chosen for this study allowed the findings to be information rich and descriptive of the phenomenon of inquiry. Affording stakeholders and other researchers the opportunity to use the information obtained to improve AA donation rates or use the methods and findings within this inquiry to investigate and / or apply to study similar situations in other populations (Ravitch & Carl, 2016).

Dependability

Dependability is established within a research study when the same methods and procedures can be duplicated (Creswell & Creswell, 2018). Dependability proposes that the appropriate research method is employed, a solid data collection plan is used, and the data obtained from the study is trustworthy and can answer the research question (Ravitch & Carl, 2016). A strong research design is imperative to attaining dependability (Ravitch & Carl, 2016).

Dependability also requires the researcher to have a reasonable explanation and rationale as to why a research method and data collection plan was used to answer the research questions. Phenomenology was used to explore the lived experiences of AAs with medical mistrust. It is through their experiences, that I obtained rich in-depth descriptions of medical mistrust to determine its influence in AA organ donation decisions. Data collection involved semi- structured interviews to allow participants the opportunity to go into detail to tell their story in the same way in which they experienced it. As a qualitative researcher, I am the instrument, using a clear concise research question that aligns with the study's problem, purpose, and triangulates with the methods and rationale for why a method is appropriate to the study helps to establish dependability (Ravitch & Carl, 2016).

Confirmability

Confirmability is the extent to which the results of study can be confirmed by others (Ravitch & Carl, 2016). Data is confirmed by several methods to decrease bias (Ravitch & Carl, 2016). Peer debriefs, peer review, data analysis, and external audits during each phase of the research process can help assure confirmability and provide the most appropriate methods to answer the research question (Creswell & Creswell, 2018; Ravitch & Carl, 2016). I communicated with my dissertation chair during data collection and analysis. My chair and committee members reviewed the themes and the participants' responses to ensure congruence. Using triangulation, different data collection methods, reflexivity by journaling my perceptions and thoughts throughout the process and being accountable to my dissertation committee through external audits I was less likely to subject my study to bias.

Ethical Procedures

Strict ethical procedures and protocols are essential to any study, but even more so with this study. Interviewing AA participants one-on-one, asking highly personal and sensitive information involving extremely delicate situations to a community that is and has been historically mistreated, requires finesse and compassion. It is imperative, I am clear and concise. I informed the participant of their rights prior to the interview and reminded them that at any time they have the right to rescind their consent and not participate (Patton, 2015). Informed consent ensures participant willingness to participate in the study without researcher coercion (Ravitch & Carl, 2016). I was mindful, to ensure my participants' comfort and privacy during their interview.

I obtained Walden Institutional Review Board ethics review and approval prior to participant selection and data collection. I was careful to protect the rights and well-being of the participants. I informed all participants of their rights without coercion; they were advised that participating in the study is voluntary and they can withdraw from the study at any time. Participants can request and obtain a copy of their interview if they so desire.

Data was secured according to Walden University protocol with all demographic questionnaires and transcribed notes, audio, and field notes stored on my private password protected computer in my home. The names of the participants did not appear on any written report of the study. The names of the participants did not appear on any written report of the study, I alone have access to the data, and it will not be shared. Each participant had a number that replaced their actual name to maintain their confidentiality and their personal information was not used for any purpose other than for this study.

Summary

The research design, rationale and methodology were identified and discussed in chapter three. Using a qualitative phenomenological approach, the lived experiences of AAs were explored, relating to their perceptions with medical mistrust determining its influence in their organ donation decisions. The research design and methodology were significant to this inquiry because it allowed me to explore the determinants that have been prominent in AA perceptions of organ donation.

Data was collected using semi-structured interviews. Each interview was recorded using an audio format. All interviews were manually transcribed verbatim to reduce researcher bias. The participant lived experiences were gathered and recorded as text and compared to the data to ensure accuracy. I focused on the participant's experience to identify common themes categories, and patterns to organize the data to help provide real answers and understanding of my inquiry. NVivo Qualitative Data Analysis (QDA) software was used to help analyze, code, organize and store the study's data.

However, most significant to this inquiry are the ethical considerations that need to be implemented to guide the sensitive nature of this research. Due to the historical and current societal landscape it is important that the ethical considerations surrounding this research are meticulously upheld and acknowledged. As the lead researcher and a member of the AA community, it is paramount that I conducted this inquiry without bias and under strict supervision to guarantee all ethical procedures and standards are maintained to ensure the most accurate representation of organ donation in the AA community is presented.

Chapter 4: Results

Introduction

A qualitative descriptive phenomenological approach was implemented to explore the results for the following research question: What are the lived experiences of AAs relating to the role of medical mistrust in their organ donation decisions? The purpose of this research was to understand the actual lived experience of AAs with organ donation and determine the level of influence mistrust had in their decisions regarding organ donation. The research also explored why mistrust continues to be a key determinant in organ donation, and why perceptions remain so prevalent within the AA community. Chapter 4 will discuss the results of the above study and outline the research study's specific characteristics regarding the study's setting, demographics, data collection/analysis, results, trustworthiness, and summary.

Setting

Due to the COVID-19 pandemic, data collection was obtained using telephone interviews. Each interview was conducted in a private, comfortable setting of the participant's choosing and lasted no longer than 60 minutes. Interviews were audio recorded using an MP3 digital and cassette tape recording device. The purpose of digital and cassette tape recordings was to ensure that I had a backup in case of recorder failure.

Demographics

Eight AA participants were recruited for the study. Participants were 18 years of age and older, able to read and write English, and expressed an interest in participating in the research study. Exclusion criteria included participants who were unable to read or write English and those who were organ transplant recipients.

A demographic questionnaire was used to gather additional characteristics about participants. The questionnaire included questions about the participants race, gender, living will status, and if they were presently an organ donor (Appendix B). Of the eight participants, two were male and six were female. None of the participants had a living-will, and of the eight participants, two female participants were organ donors. The purpose for asking participants their organ donation status or if they have a living will allowed me the opportunity to inquire about their living will and if they have included within it a decision regarding organ donation.

Data Collection and Storage

Recruitment for the participants began on the social media platforms of Facebook, Twitter, and LinkedIn. Because the social media platforms failed to yield an adequate sample size, participants were also recruited from Walden University’s participant pool. Due to the COVID-19 pandemic, I was unable to post research flyers on church bulletin boards because of the nationwide shutdown.

A research flyer (Appendix A) was posted to each social media platform and the Walden University participant pool to recruit for any AA, male or female, 18 years of age and older, able to read and write English, and interested in participating in the research study. The participants were asked to contact me by email or call the telephone number listed on the flyer. The flyer informed each potential participant that the interview would be private, tape recorded, and approximately 60 minutes long (see Appendix A).

Interested participants were emailed the demographic questionnaire (see Appendix B) and a consent form to complete and return, to acknowledge their willingness to participate in the study.

An alternative method to obtain study participants was also employed: using "snowball sampling." Participants provided the study's research flyer or contact information to other individuals who were interested in the study. The flyer also was used to begin the process allowing those participants who did not meet the inclusion criteria to eliminate themselves. The participants began the process of self-identification as AA, determining if they fulfilled both the age and English proficiency requirement. Throughout the recruitment process, interested participants were informed that participation in this study was confidential, voluntary, and they could withdraw from the study at any time, and for any reason.

The inclusion criteria for the study required participants be AA, male or female, 18 years of age and older, and able to read and write English. Once the participants acknowledged their willingness to participate in the study, they were emailed and asked to complete a consent and demographic questionnaire. Consents were sent to each participant's email address. The first paragraph of the consent confirms that each participant is AA, at least 18 years of age, English proficient, and not an organ recipient. Participant race, age, and willingness to participate was verbally confirmed before each interview. After the consent was obtained from the participant, a date and time was scheduled at the participant's convenience. The participants were instructed to pick a location that was quiet, private, and of their choosing in which to be interviewed. I chose my home office to conduct participant interviews, which provided a private, confidential, and quiet setting.

Eight participants were interviewed by telephone using six open-ended questions in a 60-minute semi-structured interview (Appendix C). During the interviews, the participants were de-identified using the numbers one through eight to assure their confidentiality, their identities stored on a private password protected computer in my office. Consent to participate in the study was also verbally confirmed prior to each interview. The data were collected using both digital and cassette recording devices. The consents, demographic questionnaires, and interview transcripts both audio and written are stored in a locker drawer and a private password protected computer in my home office.

Data Analysis

To fully understand the lived experience of this study's participants the interviews were manually transcribed verbatim. Originally NVivo QDA software was to be utilized to code, analyze and store data. However, I determined it would be beneficial to the study to perform data analysis manually to allow me to totally immerse myself into the data and personal experience of the participants. Focusing on the themes that were dominant to each participant's personal experience, I was successful in extracting rich in-depth descriptions and find common codes, patterns, and themes as I identified and organized data for analysis (Burkholder et al., 2016; Phillips- Pula et al., 2011). In the tradition of transcendental phenomenology, each manuscript was read and re read multiple times, to extract those themes that focused on each individual's personal experience. Information was divided into groups of phrases that captured the data's meaning to ensure a more complete data analysis process (Ravitch & Carl, 2016; Saldana, 2016).

I used the thematic method to analyze each participant's interview data. During my analysis of each participant's personal experience, I found more meaning in using whole statements and phrases utilizing larger portions of data instead of short words and phrases (See Saldana, 2016). This method of analysis helped me to identify statements that were unique to each participant's personal experience. Using thematic analysis allowed me to understand their full experience with the phenomena. According to Saldana (2016), thematic analysis lends itself to a higher level of understanding of the participant's experience and contributes to qualitative study and phenomenology, whose sole purpose is to seek a deeper understanding of the world exactly as the participant experiences it.

After the data were coded, and the themes, patterns, and common statements identified, redundant participant responses were grouped into categories and themes. Every question was written to provide in depth answers to the research question. My goal was to understand each participant's perception of the health care system and determine if their perception influenced their willingness to become an organ donor. Statements related to AAs perceptions and the role of mistrust in their health care in their organ donation decisions were highlighted.

The study's results were extracted from the interview transcripts and the lived experiences of eight AAs, two male and six female, 18 years of age or older, who were not organ donor recipients. The research data revealed the following themes.

Theme #1: AA providers are more respectful, supportive, and understanding than non-AA providers.

Theme # 2: AAs experience feelings of transparency and mistrust with non-AA providers.

Theme #3: AA personal experiences has resulted in their mistrust of non-AA providers in all aspects of health care.

Theme #4: Lack of knowledge regarding the organ donation process and distrust of health care systems have made AAs unwilling to become an organ donor.

Theme #5: AAs have a pessimistic outlook regarding organ donation within the Black community.

During my research, I was surprised by the amount of data obtained from the participants; some data results were more expected than others. When dealing with issues of mistrust, and the nature of this research, I had expected more unfavorable responses when questioned regarding their health care experiences from their providers. Three of the eight participants stated that their health care experience was “good,” “straightforward,” and “okay,” which was highly unexpected during the interview process. Another unexpected response from only one participant, stated that they would feel more comfortable discussing organ donation with an AA provider. This was most unusual because most participants did not feel comfortable or willing to discuss organ donation with any practitioner, as a result of the negative nature of their experiences. To further investigate these discrepant cases, it became necessary for me to encourage the participants to elaborate further to understand the nature of their answers.

Evidence of Trustworthiness

To establish evidence of trustworthiness a study must be credible, applicable to other populations, the study methods can be duplicated and confirmed by others to guarantee data is trustworthy and accurate. Evidence of trustworthiness was established using phenomenology and the thematic method to provide rich in-depth descriptions regarding the lived experiences of AAs and the role of medical mistrust in their organ donation decision making (Ravitch & Carl, 2016). Trustworthiness of this study was ensured because I used the actual participants' statements verbatim to remain authentic and represent their actual experience with the phenomenon (Ravitch & Carl, 2016; Rudestam & Newton,2015).

Credibility

To assure credibility, data were obtained and analyzed through the process of triangulation using multiple data sources to confirm the credibility of my results (Ravitch & Carl, 2016). Comparing the data obtained from my journal notes and interview transcripts allowed me to confirm the authenticity of the data collected (Rudestam & Newton, 2015). The strength of the data was certified by allowing the participants to review their interview transcripts for accuracy. The use of journal notes decreased the incidence of researcher bias to safeguard credibility and the study's trustworthiness (Rudestam & Newton, 2015).

Transferability

While there is no guarantee that my study findings could be transferable to other minority populations experiencing low organ donation rates, it is possible. The AA participants described the influence of their unique history and negative experiences as the cause of their inability to trust the intentions of the medical community who serve them.

The study results provided more rich thematic descriptions than short codes of data. To fully immerse the reader into the actual AA lived experience with mistrust and its role in their organ donation decisions, I chose to use the thematic method. The thematic method allowed for me to connect and obtain a deeper understanding of the participant's experience with mistrust and its influence on AA perceptions of health care organizations, treatments, and providers.

Dependability

Dependability is determined when a study's methods can be duplicated to obtain the same result (Creswell & Creswell, 2018). Phenomenology was used to understand and explore the actual lived experience of AAs with mistrust to show how their experience with the phenomenon shapes their health care decisions and how those decisions could influence their organ donation decisions. Collecting data using semi-structured interviews allowed participants to immerse themselves in the interview process to provide me with richer descriptions of their lived experience in the same way they experienced it. As a qualitative researcher and the instrument for my study, I felt thematic coding was more advantageous than using short words and phrases. A thematic approach allowed me to use the participant's actual descriptions and language verbatim to get a genuine understanding of their lived experience.

Confirmability

The study's data were confirmed by my dissertation chair using peer-debriefs and review. External audits were also done by my chair through each phase of my research including, but not limited to data collection and analysis to provide confirmability to my study. My dissertation chair was consulted at each stage of data collection and analysis to review the participant's responses and reoccurring themes to ensure the study's authenticity.

Study Results

The themes that were developed from this research were framed and developed from the following guiding question: What are the lived experiences of AA's relating to the role of medical mistrust in their organ donation decisions? The study's results were extracted from the interview transcripts from the lived experiences of eight AA participants, two male and six female, 18 years of age or older, who were not organ donor recipients. The following five themes emerging from the study analysis are listed.

Theme #1: AA providers are seen as more respectful, supportive, and understanding than the non-AA providers.

Over half the participants recalled only positive experiences when receiving medical care from AA providers. Participants articulated that AA providers were more supportive and aware of their needs. The AA participants were more comfortable with receiving medical care from the AA provider.

Participant one stated, "I have primarily only picked AA doctors, more specifically AA female doctors."

Participant two explained, “I recommend to my family and close friends to seek out minority/AA doctors whenever possible so they can get fair treatment.”

Participant four expressed, “I think it is a trigger to ask for an AA doctor…. I trust someone that is more concerned with my well-being…somebody that speaks my language.”

Participant five stated, “I feel more comfortable talking with an AA female doctor about female issues.”

Participant eight stated, “I do think in the United States there is a need for more AA representation in health care period.”

Theme #2: AAs experienced feelings of transparency and mistrust with non-AA providers.

The participants perceived, non-AA providers as rude, dismissive, and insensitive to their needs. Whether it was their own personal experience or that of a friend or family member, all participants recalled at least one negative interaction when seeking health care services. Over half of the participants voiced concerns with their non-AA providers. They stated the non-AA providers were suspicious of their intentions to give honest and genuine concerns and complaints regarding their health. Resulting in the participants hesitancy in believing the non-AA provider had good intentions towards providing them with fair and equitable medical care. Participants frequently expressed feelings of transparency and unimportance when interacting with non-AA providers.

Participant one stated, “I found when I went to doctors of other races, they would treat me, like I was not sick, like there nothing was wrong. Whenever, I have a doctor, that was not someone of color, they do not see you. I feel like when it comes to us they never listen. We mistrust them because when we provide our chief complaints to them they do not address them. I feel like they do not trust that we are being honest about pain level or about the problems we are having."

Participant four explained, "Most of the time, things were shrugged off. So, if I felt it was more serious, I had to continuously go back and sometimes exaggerate the symptoms to be seen even for the smallest things. I am very cautious about going to the doctor…I lost respect for them. I am not comfortable."

Participant six recalled an emergency room experience. "I remember going to the emergency room for a kidney stone. I remember being told by a white lady nothing was wrong with me and to get out! I was in shock. I felt like if I were a white boy, she would have taken care of me. It makes you keep your guard up. I also witnessed the same lady tell another older Black lady waiting in the emergency room with chest pains to sit down and wait. And the Black lady ended up dying in the emergency room. When I saw that, I thought that was careless. They do not care about us."

Participant seven explains an experience his girlfriend had. "My girlfriend had Covid, and she had been sitting in the emergency room a long time with her dad. Both were in pain and the people took their time to give them pain pills and stuff. It was really disturbing. It is their job to protect and help people. They did not do their job."

Participant eight feels, "AAs were made to believe our complaints all in our head and they often dismissed us. You always think, does this person believe me or do they think I am complaining? I try to avoid the doctor at all costs because I do not want to deal with those people. I have nothing in common with them, and I think they are just sometimes rude."

Theme #3: AA personal experiences have resulted in their mistrust of non-AA providers and in all aspects of health care.

Participants feels of inadequacy and transparency during their interactions with non-AA providers has resulted in mistrust, fear, and suspicion of the health care system.

Participant one stated, "the distrust is too strong for me at this point. How the world treats AAs, makes me feel AAs are not of value, we are only of value when you need us."

Participant two explained why they were mistrustful. "History tells me I should not trust them. When I think about what they did to my ancestors, when I think about how we were used for medical purposes, how they harvested things from us that we did not know about. We did not have any control of what they did to us and no say about what happened to us. It just keeps me in fear they are still doing that."

Participant three attributed her mistrust of health care, to her sister's health care experience." They just discounted her and said she had anxiety, then two days later she died. I feel like these experiences are why AA women and men mistrust medical doctors, therapists, or any type of clinician. We have mistrust of them, because when we do provide our complaints to them, they do not address them. When I think about Tuskegee, how can I even trust them? AAs do not trust. We do not trust doctors, or law enforcement, we do not trust a lot of people."

Participant five is hesitant, “I am cautious going to that doctor. In fact, I lost respect for him. I am uncomfortable.”

Participant six stated, “When people jump to conclusions about Black people, and anytime I get a negative reaction from someone, the doctor, even the cops. It makes you start to have your own negative perceptions about them. You do not trust me why should I trust you?”

Participant eight shared their perspective, “When I think back and put everything into perspective, I think of how does this person see me? I think back to slavery…they often dismissed us. We were made to believe it’s all in our heads, it is historic that we were mistreated. The United States has a long history ignoring Black people period.”

Theme #4: A lack of knowledge regarding the organ donation process and distrust of the health care system have made AAs unwilling to become an organ donor.

Participant negative experiences with health care and other American institutions has resulted in a continued fear of, and distrust in the systems that govern and serve society. Due to historical injustices, the participants state they are suspicious of the intentions and commitment of these systems, to provide them quality health care services. Participants negative perceptions and misconceptions of organ donation prevent them from learning how it can benefit the health of AAs.

Participant one stated, “We don’t donate because we are too afraid and distrusting to give. We are less likely to give because of our distrust. I do believe that if it were between a Black person were lying on the table and a White person waiting to receive a donor organ, I believe the Black person will not receive it. To be honest, I signed up to be an organ donor, but because of my negative experiences with health care and the experiences of people I know over the years, I can't do it, my distrust has become too strong."

Participant two's experience with organ donation occurred after the passing of her father. "They called me to see if I would be willing to donate his organs. I did not even look to see if he was an organ donor or not, I just simply said "No". I just had this belief they would not have done everything they could for him. I do not trust the medical system. History tells me I should not trust them. When I think about what they did to our ancestors, and how we were used for medical purposes, it just keeps me in fear that they are still doing that."

Participant three revealed "The only way that I would be an organ donor is if something happens to me, my organs can go to someone from the AA community or my family. That would be the only way I could be an organ donor."

Participant three also expressed unwillingness to donate, "I mean when you look back to what happened in Tuskegee, you develop a negative perception that because I am Black, no one is going to look out for me or have my best interests at heart. So, I have to be on guard to make sure my needs are being taken care of."

Participant four signed up to be an organ donor but would like their organs to go to only AA recipients. "As an AA it does not leave you with a good taste in your mouth or a positive feeling that if you are an organ donor, your organs will go to the AAs who really need them. I have not seen many AAs giving or receiving organ donations. Who is on the list? Is it mostly White people?"

Participant five explained, “Church people don’t belief in it. They say when they die, they want their body to remain intact, you know, do not cut anything out, or anything like that. I am against it personally. Somebody else may not have a problem with it, but I do not feel comfortable with those decisions.

Participant six does not believe in organ donation. “I do not believe in it. I would rather die with my organs. I believe when Black people are ill they would let you die so they can take your organs. When it comes to White folks, they work hard to keep them alive. When they see you as an organ donor, they do not try to save you. I think when it comes to Black people, I think we should not be organ donors.”

Participant seven is a young adult who discusses his parents’ views on organ donation. “My mother and father, they are really divided towards doing it. They believe family comes first. So, I think they would save their organs to help their family than a stranger.”

Participant eight is an organ donor that believes in the value of organ donation,

“Yes, organ donation saves lives. I am an organ donor. I put my trust in God, at the end of the day your time will come. The cases out there are negative and frightening. They make you not want to be an organ donor. The average Black person I believe would say, “No, you’re not touching my organs I don’t want to.”

Theme #5: AAs have a pessimistic outlook regarding organ donation within the Black community.

Participants provide insight regarding how to improve organ donation in the AA community, however participants remain unwilling and unenthusiastic to become an organ donor.

According to participant one, “There needs to be ongoing conversations that are not insulting or demeaning. When wrongs are committed against the AA community there needs to be a public acknowledgement of those wrongs to even start to repair the relationships between the medical and the AA communities.”

Participant two explained, “I think just more networking is needed within the AA community. Getting out there meeting the people in the community. Sharing information and basically educating us on what we need to know, showing us that they are genuine want to understand us and not hurt us, or keep information from us that is important for us to know”.

Participant three revealed, “I think honestly, the first step would be acknowledging that the AA community was done wrong, I know that sounds simple, but I think it is a start. I feel like because the wrongs committed were years and centuries ago, people tend to say you need to get over it. It did not happen to your generation. We do not trust for this reason. We do not trust medical doctors, we do not trust law enforcement, we do not trust a lot of people.”

Participant four stated “If someone came in that looked like me and understood my concerns, explained things, and took my symptoms seriously I think would be more willing to discuss organ donation with them. I would say research organ donation, you will feel more comfortable donating or not. Knowledge is power. Research and understanding would make it more of a positive thing and increase Black people's willingness to donate."

Participant five stated, "I would like to see more AAs receive AA transplant organs. If more AAs go public with their decisions it might help more AAs understand that organ donation can have a positive outcome in our community. They would understand and see that it is okay to receive a transplant, if you educate the AA youth early regarding organ donation, I feel that would help to decrease their fears and suspicions regarding organ donation."

According to participant six, "No nothing, can be done to improve organ donation in the AA community, the damage is already set." "White people have done so much to AAs, they have killed us, destroyed our communities, these are some of the reasons I do not trust. I feel like they really don't care about us. I don't trust the government or the medical community, they do not have the best intentions towards the AA community."

Participants seven response was brief, but also was pessimistic in nature. When asked what can be done to improve organ donation in the AA community this participant states "Nothing".

Participant eight's response was also doubtful and suspicious of improving organ donation in the AA community, "Right now I have no trust. My family and I do not trust medical community. My family believes that when you go into the hospital you will die, so leave me at home. I think history and the media has a lot to do with why there is mistrust in AAs. The negative perceptions of AAs in the media makes me distrustful and makes me fearful and afraid. However, because of my beliefs I will still be an organ donor. I think healthcare reform will help. Bring AA leaders in the loop and allow them to participate in the policies and decision-making regarding organ donation."

Summary

Chapter four described the study's setting, demographics, data collection, data analysis, evidence of trustworthiness, and discussed the study's results. My study explored the lived experiences of AAs, regarding the role of medical mistrust in their organ donation decisions. The AA participants interviewed had several common themes that indicate medical mistrust among AAs still exists, and its presence still negatively affects how AAs perceive the medical community and their medical decision-making. A common theme among all AA participants is their distrust of the medical community. African American distrust is a direct result of a long history of slavery and mistreatment from the medical community. This mistrust causes them to be fearful and suspicious of the intentions of many non-AA health care providers. Their distrust of the medical community makes AAs to be unwilling to become an organ donor and distrustful of the organ donation process. Chapter five will explore my results, providing an more extensive explanation and interpretation of my findings, explore study limitations, look at recommendations and provide implications for positive social change to improve organ donation in the AA community.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This qualitative study was designed to understand the lived experiences of AAs, allowing the AA participants to describe their health care experience, to determine if mistrust influences their perceptions and attitudes towards organ donation. A deeper understanding of the AA experience with health care could help to provide insight on how to improve the negative perceptions AAs have of the medical community and help to increase AA willingness to become an organ donor. This research can further aid in developing strategies towards improving the relationship between the AA and medical communities to increase AA quality of care and expand the access to medical care in many communities of color where the members are suspicious and hesitant to seek care. Chapter 5 will summarize and interpret my findings, address the implications and limitations of this study, and provide recommendations for future research.

Interpretation of Findings

According to the literature, AA organ donation decisions and behavior are due to several reasons, but mistrust was cited as a major determinant of AA unwillingness to become an organ donor (Arnett et al., 2016; Kinlock et al., 2017; Morgan et al., 2015; Quick et al., 2016; Williamson et al., 2017; Williamson et al., 2018). The purpose of this research was not to dispute the existence of mistrust but understand why it still continues to be so prevalent in the AA community and to explore what exists within the lived experience of the AA that perpetuates their feelings of mistrust making them unwilling to become an organ donor.

There were five themes that emerged from the data and were noted in Chapter 4. The following themes were highly significant to the study and were instrumental in providing answers to the research question relating to the lived experience of AAs regarding the role of mistrust in their organ donation decision-making. The findings were extracted from the actual statements of each participant's lived experience.

Theme #1: AA providers are seen as more respectful, supportive, and understanding than the non-AA providers.

In Theme 1, the participants stated the need for more AA representation in health care. In the participants' experience, AA providers were more sensitive to the needs of their AA clients. The participants stated they chose AA providers because of their negative experiences with non-AA providers. The participants described a more positive and supportive relationship with their AA provider.

The role of health care providers was extremely important to improving AA access to quality health care. According to the literature, the role of the health care provider is to encourage patient-centered care and foster positive relationships with their clients (Cuevas et al., 2019; King & Redwood, 2016). Participants 1, 2, 4, 5, and 8 stated they felt AA providers were more sensitive to the needs of AAs. A majority of the participants chose AA/minority doctors because they felt more respected and validated during their doctor visit and had an overall positive experience with AA providers.

AA mistrust of the health care community continues to affect interprofessional relationships, reduce AA compliance, and impact health care outcomes significantly (Cuevas et al., 2016). Increasing the number of AA providers can help AA patients feel more comfortable with the care they receive because they identify with a provider from their same cultural background. According to my data, the participants trusted AA providers to be more understanding of their experiences as AAs, because the provider was of the same racial background and community. My study participants were more trusting of the AA providers because in their experience, they were able to communicate more effectively with an AA provider than a non-AA provider.

The participants described their experiences with non-AA doctors as uncomfortable, and the provider's attitude as dismissive. A few participants stated the non-AA providers were rude and, disrespectful during their interactions. However, several participants expressed their dissatisfaction with the non-AA provider, stating the provider did not listen, and remained unwilling to address their concerns. The participants indicated that they do not feel as though their non-AA provider believed their complaints were truthful. The participants believed they were distrusted by the provider, resulting in participant feelings of suspicion and distrust of the non-AA providers intentions. According to Cuevas et al. (2016), AA patients felt discriminated against because the non-AA clinicians never addressed or acknowledged their concerns, The AA patients had very few opportunities to communicate their needs, resulting in their decreased level of engagement in their plan of care (Cuevas et al., 2016).

The participants of my study described feeling more at ease with the AA provider because they felt the provider had a better understanding of the AA experience, and culture than the non-AA provider. The participants indicated that the AA provider had a better understanding of their concerns and needs when providing them health care services. This theme is confirmed in Cuevas et al. (2016), who indicated that AA doctors are preferred by AA patients because they were viewed as more willing to listen to the AA patients concerns and supply the patient with the education needed to make more informed decisions regarding their health care.

Theme #2: AAs experienced feelings of transparency and mistrust with non-AA providers.

All eight participants expressed feelings of mistrust when non-AA providers disbelieved their symptoms and invalidated their health care concerns. The participants perceived themselves as invisible, viewed as unimportant or disposable members of American society. The participants expressed feelings of transparency when cared for by non-AA providers. According to the participants these feelings of unimportance and transparency has led to their continued suspicion of the intentions of non-AA providers and their mistrust of all aspects of health care community.

When questioned about the quality of their health care and the relationship with their provider, the participants responded accordingly: “They do not see, listen or care about us.” The literature confirms the AA participants’ experiences with non-AA health care providers. In Cuevas et al. (2016), the AA participants reported feelings of being “skipped over,” leading to their dissatisfaction with their non-AA health care providers and mistrust of the medical community. In Cuevas et al., the participants stated they mistrusted their non-AA providers because they felt their opinions were devalued and concerns ignored. According to Cuevas et al. (2016), AA health providers were more compassionate and empathetic to the needs of their AA patients.

The negative experiences of the participants with their health care practitioners are confirmed by the literature. According to King and Redwood, (2016), non-AA providers are susceptible to decisions based on stereotypes and bias that can impair their judgements regarding the needs of their AA patients. The stereotypes and misconceptions of AAs from non-AA health care providers negatively affect the AA perceptions and continues their mistrust of the medical community (Cuevas et al., 2016; King & Redwood, 2016; Smirnoff et al., 2018).

Hammond, (2010) confirms that AA feelings of vulnerability during health care encounters is created by unfavorable experiences, resulting in negative opinions regarding their health care. As these undesirable experiences accumulate in the mind of the AA individual, it can make them suspicious and distrustful of all future interactions with the health care system (Cuevas et al., 2016; Hammond, 2010). The mistrust AA participants described is a by-product of their feelings of transparency and their perception of the wrongs committed against them. Their negative experiences have perpetuated feelings of being unwelcome, unimportant, and transparent to the society in which they belong. According to the literature and confirmed by this research, it is these experiences that continue the negative perceptions AAs have of the world around them, that have led to their continued suspicion and distrust (Cuevas et al., 2016; Hammond, 2010).

Theme #3: AA personal experiences have resulted in their mistrust of non-AA providers in all aspects of health care.

The negative feelings of transparency and mistrust in the participant's interactions and experiences with their non-AA health care providers have a profound effect on their relationships with the health care community. According to my data, poor communications, a lack of cultural understanding, and concern on the part of the non-AA provider has caused a persistent and chronic negative relationship between the AA patient and their non-AA health care provider, creating a general overall mistrust of the medical community. Cuevas et al. (2016) confirms the results of my study, recognizing AA vulnerability is associated with their negative experiences and perceptions. AAs who feel overlooked and dismissed when voicing their concerns to their non-AA health care provider, are more likely to be distrustful (Cuevas et al., 2016; Hammond, 2010).

Participant 1 recalls a story told to her by a friend: "A friend of mine had Covid and came to the hospital begging for help. He was laughed at and finally said 'Forget it. I would rather take my chances at home.' He was terrified for his life." The participants were less likely to trust because they had experienced too many negative outcomes. These experiences continue to fuel their distrust of the medical community. King and Redwood (2016) confirm that there is evidence AAs experience racism in health care. Chronic exposure to racism creates an adverse response in the AA community, producing the negative attitudes that continue to damage their perceptions of the medical community (King & Redwood, 2016).

Participant 2 states simply, "History tells me I should not trust them." AAs are mistrustful and suspicious of the health care community because their past experiences and history has taught them to react this way (Arnett et al., 2016; Kinlock et al., 2017; Quick et al., 2016; Robinson et al., 2015; Williamson et al., 2018). As noted by King and Redwood (2016), AA perceptions of health care have been negatively shaped by a long history of unfair treatment and medical atrocities, deeply affecting their understanding and trust in the intentions of the medical community. AA mistrust plays an important role in why AAs remain suspicious and fearful of the intentions of the medical community.

The AA participants of my study indicated feelings of unimportance and transparency to the society in which they belong. These feelings of not belonging or being unimportant only strengthened the participants level of mistrust of the world around them. My findings are further confirmed by Hammond (2010) and Williamson et al. (2018), as negative experiences occur, mistrust grows in the individual until it creates negative perceptions and doubt regarding their personal safety. According to Hammond and Williamson et al., when a person feels unsafe, they are more likely to internalize their negative experience, causing them to mistrust and expect negative outcomes. The ongoing negative perceptions of my study participants, expressing their sentiments that "no one cares about Black people," along with the historically negative perceptions AAs have of health care is confirmed in literature. A history of slavery, medical mistreatment, racism, and the anticipation of further ill-treatment is what continues to influence AA mistrust of health care (Cuevas et. al., 2016; King et. al., 2016; Robinson et al., 2015; Williamson et al., 2017; Williamson et al., 2018).

Theme #4: A lack of knowledge regarding the organ donation process and distrust of the health care system has made AAs unwilling to become an organ donor.

During the interviews, participants' knowledge of organ donation and its process was limited. The participants required more education regarding organ donation. Their need for additional education in the organ donation was obvious by their descriptions of their experience and knowledge regarding the organ donation process. The literature does confirm mistrust of the medical community and decreased awareness of the organ donation procedure and process is a major reason for AA unwillingness to donate (Harding et al., 2017; King et al., 2016; Robinson et al., 2015; Williamson et al., 2017).

Negative perceptions and experiences with health care greatly influenced the participants' views regarding organ donation. Several participants stated they were fearful of the intentions of non-AA health care providers and did not trust them to be fair in their treatment. According to King et al. (2016) and Robinson et al. (2015), AAs have a complex relationship with the medical community, AAs have been subjected to inhumane medical treatments and practices that were so traumatic, they find it challenging to look beyond their distrust to acknowledge the positives of organ donation. As Participant 1 stated, "So I understand the importance of it, and to be honest when I initially signed up to be an organ donor, I was proud of that decision. However, my negative experiences with health care and the experiences of the people I know over the years makes me distrustful and I am sorry, I cannot do it. The distrust is too strong for me at this point. We do not donate because we are too afraid and distrusting to give." Participants stated that a long and traumatic history of AA enslavement and medical mistreatment is the reason they continue to distrust the medical community. AAs recall memories of racism and discrimination during their interactions with the medical community (Cuevas et al., 2016; Hammond, 2010).

Other barriers found significant to organ donation included questions regarding the fairness of the organ donor process, fear of premature death, and religious beliefs and superstitions. The participants of my study questioned the fairness of the organ donation process, fearing that because they are AA all life-saving efforts will not be taken to save their lives. My data confirmed participants do not trust organ donation because of their mistrust of the medical community and the belief that it benefits the medical needs of Caucasian people. According to Williamson et al. (2017), AAs believe that the organ donation process favors Caucasian patients and doctors and will provide inferior care to an AA organ donor to have the opportunity to harvest their organs. Issues of body disfigurement were also discussed by the participants. The AA participants were unwilling to become an organ donor because they believed a person's body must remain intact even in death. Religion and spiritual beliefs are deeply rooted in the AA community, Quick et al. (2016) confirms the AA belief that the body must remain intact so the spirit can reach eternal life.

Some participants did not believe organ donation benefits AAs. High levels of health care mistrust were detected during the interviews. The participants stated it is important to remain alert and vigilant because no one looks out for the well-being of AAs. Participants described their own personal negative experiences and the unfavorable encounters of other AAs as a significant cause of their fear and mistrust of the health care community to care for and support the interests of AA people. Distrustful of the health care system, the AA participants also stated government institutions are misleading and not truthful to the AA population. Some participants expressed their belief that the majority of American institutions are discriminatory and deceptive to AAs.

Theme #5: AAs have a pessimistic outlook regarding organ donation within the Black community.

The participants were asked what can be done to improve organ donation in the AA community. There were a few positive responses but overall, the majority of the participant perceptions regarding organ donation were not optimistic. Participant 6 and 7's responses were discouraging and pessimistic, "nothing, if you don't trust it, you don't trust it. The damage is already set." The participants continued to recall stories regarding the Tuskegee syphilis experiment and AA slavery is significant. None of the participants had personal experience with either occurrence, however, all the participants were aware of these historical events and described their knowledge of them as a reason for their distrust. The participants knowledge of these negative occurrences prevented many of them from even considering organ donation. According to Hammond (2016), Kinlock et al., (2017) and Smirnoff et al., (2018), the current socioeconomic climate and the historical mistreatment of AA people have made it difficult for many AAs to trust governmental institutions intentions regarding improving the lives of the AA people.

Participants expressed the need for an ongoing conversation between the AA and the medical community, acknowledging the hurt and mistreatment perpetrated against the AA people. Participants believed in educating health care providers in cultural sensitivity, to improve communication and meet the emotional needs of AAs. Participants believed this may help to improve the health provider’s understanding to why AAs are mistrustful and suspicious of the medical community. The participants stated, if non-AA providers continue to lack understanding how to communicate with the Black community there will continue to be AA mistrust of the medical community and unwillingness to become an organ donor. However, participants do state they felt there is need for an ongoing discussion to bridge that gap, encourage more non-AA providers to become aware and understand the unique psychological and physiological needs of the AA patient.

Participants indicated they recognized the need for more education regarding organ donation, and its process. AA understanding and awareness of the desperate need for organ donation in the AA community, is critical to addressing the severe health disparities facing the AA community. The participants expressed their belief that a better understanding of organ donation and its process would help to increase AA willingness and acceptance of organ donation. A few participants also expressed a need for more positive media coverage regarding organ donation in the AA community is crucial to increasing AA awareness and understanding that organ donation can help improve the health of AAs.

My study had two significant and unexpected findings. The first finding indicated that AAs were more willing to discuss organ donation and consider becoming an organ donor with an AA provider. Participant 4 stated she would be more comfortable in discussing organ donation with an AA provider. In theme 1, the participants expressed an increased level of comfort when cared for by an AA provider. However, the participants in theme 1 failed to associate their increased level of comfort as an opportunity to discuss organ donation with their AA provider.

As I referred to the literature, an existing finding, crucial to improving organ donation in the AA community confirmed my research findings. More than half the AA participants stated they felt more at ease receiving care from an AA provider but, only one participant out of the eight mentions a discussion regarding organ donation with an AA provider. The literature confirms my data, the race of the health care provider often goes unnoticed but is significant to improving AA patient and health care provider relationships (Cuevas et al., 2016). According to King et al., (2016) the underrepresentation of AAs in health care and their continued mistrust of the medical community creates an opportunity for increased health disparities and poor health outcomes. The more AA health care providers available for AA patents to choose from, could help to improve their comfort receiving treatment and having discussions regarding organ donation.

A most of the participants expressed feelings of transparency and mistrust of non-AA providers. Most of the AA participants in my study recalled negative experiences with health care that have resulted in their mistrust of the medical community. However, when asked how they feel about the care they have received by their provider, six out of eight expressed that not all health care received was negative.

Over half of my study participants stated not all their experiences in health care were negative, being unsure of what this finding implies, I looked for guidance in the literature. In Cuevas et al., (2016) the AA males in the study stated that race was not important if the doctor was competent. Can this shift in AA perceptions be attributed to the increase in cultural sensitivity training in health care organizations? Cuevas et al., (2019) asserts patient-centered approaches help to increase cultural awareness in the medical professionals and improve the relationships and perceptions AAs have of the medical community. While not all care given to the participants of my study by non-AA providers was considered as negative. The results confirm that when an AA does experience mistreatment by a non-AA provider it continues to cause the individual to think back on previous negative experiences with a renewed sense of mistrust and suspicion.

My study has confirmed AA medical mistrust has a direct relationship to the participants negative experiences and perceptions of the medical community (Hammond, 2016; Kinlock et al., 2017; Smirnoff et al., 2018). Participant experiences with medical mistreatment, societal misconceptions, and a generational knowledge history of slavery continue to fuel their negative views of the health care system (Hammond, 2016; Kinlock et al., 2017; Smirnoff et al., 2018). These variables are consistent with the literature and has continued to be the result of an ongoing negative perception Black people have of the medical community, making them unwilling to become an organ donor (Arnett et al., 2016; Cuevas et al., 2019; Kinlock et al., 2017; Morgan et al., 2015; Quick et al., 2016; Williamson et al., 2017; Williamson et al., 2018). These negative experiences have caused distrust and suspicion in the participants, making them fearful of organ donation and hesitant to learn about the organ donation process (Cuevas et al., 2016; Hammond, 2010; King & Redwood., 2016; Williamson et al., 2018).

I used a descriptive transcendental phenomenological approach to obtain real data in the actual words of the participants, describing their experience in the same way they experienced it (Cilesiz, 2011; Lopez & Willis, 2004). The participants real experience with the phenomenon is what motivates them. When one can understand an individual's experience, you can understand what motivates their decisions and behaviors (Lopez & Willis, 2004). Real experiences were collected from the participants regarding their experiences with the health care community. For the participants, it was a combination of these negative experiences, a history of slavery and the societal injustices committed against AAs that influenced their unwillingness to be an organ donor.

SCT was also utilized to understand if the participant's own lived experience and environment with medical mistrust, influenced their decisions and behavior towards organ donation (Thojampa & Sarnkhaowkhorm, 2019). In SCT the individual learns from their experience and from the environment around them. The individual gains knowledge and understanding of the world around them and make a conscious decision to either change or not change their behaviors or decisions based on the knowledge they obtained from their own experience or the experiences of others (Thojampa & Sarnkhaowkhorm, 2019). The participants in my study experienced very negative interactions with the health care community. Based on these negative experiences, and the knowledge of past and present mistreatment of AAs, the participants internalized their negative experiences and felt it very difficult to trust the health care community, causing them to be unwilling to become an organ donor.

Limitations of the Study

Limitations are situations and circumstances of the study that are out of the researcher's control (Simon, 2011). Due to the nationwide pandemic, it became necessary to use other means to collect data. In person interviews were neither safe nor an option, so telephone interviews were used to gather data. Limitations of my study included the participants limited knowledge and understanding of what organ donation is and how donor organs are allocated.

Recommendations

My findings suggest it imperative to find strategies to improve communication between AAs and their health care providers. The health care providers are specifically identified because, they are the first to interact with the AA patient and represent the face of the health care system. It is important to provide ways to improve communication to reduce negative interactions and situations that AAs perceive as discriminatory to decrease their mistrust of the medical system and improve patient-provider interactions (Cuevas et al., 2016; Cuevas et al., 2019; Williamson et al., 2018).

During the interviews, the participants were asked what could be done to improve organ donation in the AA community? Seven out of eight participants expressed the need for an open and honest conversation to take place between AAs and the health care community. The participants were very specific in their suggestions, stating acknowledgement of past wrongdoing to the AA community and accountability of this mistreatment is the only way to begin to improve the relationship between health care organizations and the AA community.

Further research is needed to continue discussions regarding AA perceptions of discrimination and increasing cultural sensitivity in health care workers to create more awareness of AAs culture and identify ways to support, communicate, and advocate for the AA patient (Cuevas et al., 2016; Cuevas et al., 2019; Williamson et al., 2018). It is mandatory for health care providers to be sensitive and empathetic to the AA experience in America. Health care providers need improved awareness of their history and culture to advocate and understand the needs of the AA patient.

During my study, I have found that my AA participants lacked knowledge of organ donation and understanding of the organ donation process. There is a need for more education regarding organ donation in the AA community. An understanding of organ donation can help to dispel the misconceptions and myths AAs still have regarding the organ donation process. Increased awareness of the growing health disparities in the AA community, hypertension, heart failure, diabetes and kidney failure make continued discussions regarding organ donation significant because these are the very chronic illnesses that result in a higher need for AA organ recipients and donors.

Implications

This study can elicit positive social change for the AA community, health care professionals, and society. The results of the study are an important first step towards creating a conversation within the health care community to develop awareness, understanding, to search for solutions to improve organ donation in the AA community. This study can provide important information to develop programs to address the fears and concerns of the AA community regarding organ donation. These programs can begin to help address the fears and concerns of the AA community regarding both health care and organ donation. An increase in AA donors will decrease the burden on society to seek additional donors from other ethnic groups and reduce the financial burden of chronic illness in the AA community. The implications of this research have the potential to save lives and improve the quality of life in AA patients who suffer from life threatening disease and organ failure.

The need for organ donation is critical to the health of the AA people. This life saving treatment is important to improving the severe health disparities and negative health outcomes that continue to plague the AA community. However, to address the need for improvement in AA organ donation it is imperative to improve communications and establish trust between AAs and the health care system. African American distrust of the health care system is pervasive and has deep roots in medical mistreatment and slavery. This negative history keeps AAs fearful, suspicious, and doubtful of the intentions of the medical community. Improving the relationship between AAs and the medical community will not be easy, but it must be done to improve the health outcomes of AAs suffering from critical illnesses and debilitating disease.

As a health care practitioner and educator, I recognize that a positive social change starts with those of us who care for and interact with AA patients every day. It begins with really listening to our patients and addressing their needs without prejudice or judgement. It ends with a smile, a kind word, advocacy, and most of all education regarding their health. Positive and compassionate care is the only way to begin to dispel the deep mistrust present in the AA community. Trust is key to improving AA health outcomes, health care quality, access, and patient compliance. With trust comes an opportunity for the health care professional to improve the health outcomes of the AA patient.

Conclusion

AAs live in a historical trauma that becomes retriggered every time something negative happens. Unfortunately, due to the COVID 19 pandemic, there has been an increase in negative events in the AA community. The increase in negative occurrences, combined with past offences against the AA people has not alleviated their mistrust of American institutions, i.e., health care. In fact, it has encouraged AAs to respond with a heightened sense of suspicion and fear. The fear created from feelings of inadequacy, transparency, and unimportance, results in continued AA mistrust, fear, and suspicion. Feelings of distrust are created from the negative experiences AAs have when interacting with the environment around them. The participants expressed feelings of unworthiness and transparency when interacting with their non-AA health care provider, “They don’t see or hear us!” These negative experiences and perceptions continue to create AA distrust in the intentions of the organizations and institutions who provide the society’s rules and services. The participants indicated they felt that if those who make the rules within society have a history of treating AAs unfairly, what will prevent further mistreatment? Feelings of fear and distrust have permeated the AA response to health care and causing disparities in AA health care quality and compliance. The result is a continued mistrust of the health care community and health care treatments like organ donation, that are proven to save lives and improve AA quality of life.

Ongoing research is necessary to develop policies and practices to improve AA attitudes and perceptions of health care. The introduction of new practices may help health care providers improve their medical provider-patient interactions with AAs. It is imperative health care providers and agencies continue to explore the role and influence of AA mistrust in organ donation. Exploring the role and influence of medical mistrust in organ donation has the potential to create positive social change by combating the negative beliefs and myths that prevent AAs from becoming organ donors

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Appendix A: Research Flyer for Participant Recruitment

Research Volunteers Needed

My name is *********. I am a Ph.D. student at Walden University conducting research regarding the role of medical mistrust in African American organ donation decisions. Please call or email me if you would like to hear more about this study.

To participate you must

- Be an African American male or female over 18 years of age
- Able to read and write English

You will be asked to participate in one telephone interview session that allows you to share your views regarding organ donation that is

- Private
- Tape-recorded
- 60 minutes long

I am available to discuss this in more detail with you. I can be contacted at *******@*******.edu so that I can answer any questions you may have about participating in the study. Please feel free to share this flyer with other individuals you feel may be interested in participating in this study.

Please Call or Email if you have questions
Email: ** @******.edu**
or *-***-******

The Walden University Institutional Review Board, study # is **02-02-021-0446595** and has approved this study.

Appendix B: Demographic Questionnaire

Date____________ Participant Identification # __________________

Hello, my name is ********* a doctoral student at Walden University and I am very happy that you have indicated an interest in participating in my research to understand the role of medical mistrust in African American organ donation decisions. The study will help me gain understanding of how medical mistrust challenges African American organ donation decisions. To be sure you qualify to participate I would like to ask you a few questions.

Are you an African American: Male? Female?	 Yes Yes	 No No
Are you an organ donor?	Yes	No
Do you have a Living Will?	Yes	No

Appendix Table C: Interview Protocol

Interview Protocol

Date of Interview:

Location of Interview:

Start Time: **End Time:**

Code of Interviewee:

Name of Interviewer: ***********

Recording Mechanism:

Introduction to Interview Session:

Hello, Mr. or Ms. (Participant's Name), thank you for taking your time to meet with me today. As I have already shared with you, this interview will contribute to the information gathered for a researched intended to learn more about the experiences and perspectives of African Americans related to the role of medical mistrust and its influence on their organ donation decisions.

You have been asked to participate because you are an African American 18 years or older and willing to share your experiences with me. The questions I will ask you and the answers you give me will be about you and your unique experience. You may be familiar with the conditions of some friends and family members. However, you can share this information with me but, this is about your own experience and perspective. There are no right or wrong answers. All answers are welcomed and helpful. Please feel free to provide as much detail as possible that you are willing to share. If you decide not to participate in this research study, you are under no obligation to continue and you may withdraw your decision to participate at any time without repercussions. I will be recording the interview. This will allow me to have an accurate record of what you shared with me and not rely on my memory. It will also help me listen attentively to you without needing to write everything down. However, I will be taking some notes as well. Do you have any questions at this time? I would like to begin by confirming that you voluntarily consent to be a participant in this study, and you are an African American 18 years of age or older?

Interview Questions

RQ: "What are the lived experiences of AAs relating to the role of medical mistrust in their organ donation decisions?"

Interview question 1: **Tell me about your experience as it relates to the care you have received from your medical provider?**	**Prompt questions r/t the cultural awareness of the medical community regarding AAs:** **Do you believe they have been sensitive to your needs?** **Can you give me some examples when they were sensitive or insensitive?**
Interview question 2: **Can you describe any experience with a health care professional that may have**	**Prompt questions r/t health care providers:** **What is your reaction to this experience?**

influenced your perception of the medical community?	**How has it influenced your perception of the medical community?**
Interview question 3: **Describe any experience where you believe you received a lower quality of care because you are AA?**	**Prompt questions r/t health care perceptions** **What is your reaction to this experience, has it influenced your perception of the medical community?**
Interview question 4: **Can you describe any experience that has positively influenced your beliefs regarding organ donation?**	**Prompt questions r/t organ donation:** **How has your personal experience positively influenced your feelings about organ donation?**
Interview question 5: **Can you describe any experience that has negatively influenced your beliefs regarding organ donation?**	**Prompt questions r/t organ donation:** **How has your personal experience negatively influenced your feelings about organ donation?**

Interview question 6: **What do you believe could be done to increase organ donation in the AA community?**	**Prompt questions r/t increasing Organ donation in the AA Community:** **Can you describe some specific ways to get the attention of the AA community, to encourage more AAs to consider becoming an organ donor?**

Closing Statement

I want to thank you very much for taking the time to share your story with me today. I very much appreciate your contribution to this study. You will receive a transcript by email of today's interview, when you receive it please check it for accuracy. If you think you need to reach out to me with further information, questions, concerns, please do not hesitate to email me at ******@******.edu or call ***-***-****