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A Comprehensive Literature Review of the Relationship between Distrust in the United States  
Health Care System and Organ Donation among African Americans

By

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MPH Candidate, 2017

Behavioral Sciences and Health Education

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A Comprehensive Literature Review of the Relationship between African American Distrust in  
the United States Health Care System and Organ Donation

By

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Thesis Committee Chair: Kimberly Jacob Arriola, PhD, MPH

An abstract of a thesis submitted to the faculty of the Rollins School of Public Health of Emory  
University in partial fulfillment of the requirements for the degree of Master of Public Health in  
the Department of Behavioral Sciences and Health Education

2017

## **Abstract**

### **A Comprehensive Literature Review of the Relationship between African American Distrust in the United States Health Care System and Organ Donation**

By Trish P. Miller, MBA

#### **BACKGROUND:**

African Americans are in need of life saving organ transplantation due to overrepresentation among End Stage Renal Disease (ESRD) patients, however African Americans do not donate organs on par with need. Distrust in the health care system is acknowledged as a significant barrier to African Americans' lack of commitment to organ donation. Using the Conceptual Model of Distrust in Health Care, this comprehensive literature review will study the pathways between health care distrust and organ donation among African Americans to better understand how this barrier affects the decision to donate.

#### **METHODS:**

Three databases were searched using a keyword search yielding 218 publications. Once duplicates were removed, 43 publications were screened for inclusion. Twenty-four publications were excluded after first stage screening, and an additional five were excluded after second stage screening, resulting in 14 publications for review. Each was categorized into three types of health care distrust based on the Conceptual Model of Health Care Distrust: distrust of health care systems, distrust of medical professionals, and distrust of the organ allocation system, and analyzed to see how they may influence organ donation behaviors among African Americans.

#### **RESULTS:**

Fourteen publications of empirical studies that focused on the relationship between health care distrust and the decision to donate among African Americans in the United States were reviewed and analyzed. The outcomes focused on cadaveric organ donation intentions, donation attitudes, and/or willingness to donate; with one publication focusing on cadaveric brain donation intentions. Results indicate that with three exceptions, all 14 studies found that the three types of distrust were associated with organ donation behavior. The exceptions are studies that found no association between distrust of the health care system and organ donation: Russell et al. (2012); Robinson et al. (2015), and Jefferson et al. (2011).

#### **CONCLUSION:**

The literature suggests a consistent association between distrust in the health care system as a whole and the decision to donate organs among African Americans. Programs and interventions should focus on methods to improve health care trust to improve African Americans' willingness to donate organs to increase the donor pool and improve access to transplants for those in need.

## **Dedication**

This work is firstly dedicated to reason I am who I am and the reason for this research, my father, William H. Happer, Jr. May this research give someone the needed motivation to increase the number of African American donors to give those in need of life saving organs the same opportunities to a quality of life as others. Daddy, I share this milestone with you.

Lastly, this work is dedicated to the best two people in my life, my drivers, my strength, my light  
– Ava & Evan Miller.

## **Acknowledgements**

This work would not be possible without the guidance and dedication of my chair, Dr. Kimberly Jacob Arriola, and the warm and kind spirit of my committee member, Nakeva Redmond. Thank you both for your support, long hours, sacrifice, and dedication to my success.

I would also like to acknowledge my committee member, Dr. Claire Loe, who was unable to see this work to completion as she lost her battle with cancer in November of 2016. Claire's support and guidance as both a colleague and friend has been amazing and a source of strength during this process.

Lastly, but in no way least, I would like to acknowledge my best friend and partner, Donte Perkins, to whom I am greatly indebted for all of the love, encouragement, pushing/shoving, and support you have shown to get me to the finish line.

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## **Chapter One - Introduction**

### **Chronic Kidney Disease in the United States**

Chronic diseases affect a significant proportion of Americans, with 45% of all Americans suffering from at least one chronic disease.<sup>1</sup> Chronic diseases account for more than two-thirds of all deaths.<sup>1</sup> African Americans suffer and die disproportionately from chronic diseases such as cardiovascular disease, diabetes, obesity, and their related outcomes such as hypertension and kidney failure than other races due to increased health risk factors.<sup>2,3</sup>

Chronic Kidney Disease (CKD) is not considered to be one of the top five chronic diseases, but its footprint is significant in that one in ten American adults, more than 20 million, have some level of CKD.<sup>4</sup> Chronic Kidney Disease is a condition in which the kidneys malfunction and as a result cannot filter blood as well as healthy kidneys. Approximately 50% of adults aged 30-64 are expected to develop CKD in their lifetime.<sup>5</sup> Risk factors for CKD include chronic diseases such as diabetes and hypertension. Current research suggests that approximately one out of three adults with diabetes and one out of five adults with high blood pressure has CKD.<sup>4</sup> Family history, among other risk factors such as obesity, high cholesterol, lupus and cardiovascular disease are also predictors of CKD.<sup>5</sup> African Americans experience higher rates of diabetes, hypertension, and heart disease, and as a result, tend to be more susceptible to kidney disease. Chronic Kidney Disease left unchecked may lead to kidney failure, and kidney failure affects African Americans three times the rate it does Whites.<sup>6</sup>

### **Chronic Kidney Disease and the Treatment of End Stage Renal Disease**

Chronic Kidney Disease will commonly lead to End Stage Renal Disease (ESRD) if left unmanaged. End Stage Renal Disease is a condition in which the kidneys completely fail and are unable to remove toxins and waste from the blood. In 2011, over 100,000 patients in the U.S.

started treatment for ESRD, where diabetes and high blood pressure were listed as the primary cause for seven of ten new cases.<sup>5</sup> The incidence of ESRD is more prevalent in minority populations, with African Americans being approximately three and a half times more likely to develop the disease than Whites; and Hispanics being approximately one and a half times more likely to develop ESRD than non-Hispanics.<sup>5,7</sup>

The treatment options for ESRD are limited, and are typically hemodialysis or kidney transplantation. Research suggests that kidney transplantation is the best option for most ESRD patients and is associated with decreased mortality and morbidity, and also suggests that transplant patients experience an increase in quality of life over hemodialysis treatment.<sup>8</sup> There are two options for kidney transplantation: Deceased Donor Kidney Transplantation and Living Donor Kidney Transplantation. In 2016, African Americans represented 14% of all deceased kidney donors, whereas Whites represented 68%.<sup>9</sup>

### **Need for Organ Donation**

The need for kidney transplantation far exceeds the supply of available organs, and each year the number of patients with ESRD listed for kidney transplantation increases, with only a minimal increase in available kidneys. According to the literature, there are less than 17,000 donor kidneys available each year for the 100,000 patients on the waiting list.<sup>10</sup>

According to April 2017 data on the Organ Procurement and Transplantation Network (OPTN) website, there are approximately 118,131 people in need of an organ transplant.<sup>11</sup> Kidneys are the most commonly transplanted organ and the most in need.<sup>12,13</sup> As of April 2017, 97,860 candidates were on the kidney donor waiting list. This total amounts to 82.8% of the total organ waitlist population.<sup>9,14</sup> On average, 22 people die every day from the lack of available organs

for transplant.<sup>12</sup> Based on 2016 OPTN data, there were 15,946 living and deceased organ donors (see Table 1).<sup>15</sup>

**Table 1: Living and Deceased Organ Donors by Ethnicity from 2006 to 2016**

	Total	2016	2015	2014	2013	2012	2011	2010	2009	2008	2007	2006
All Ethnicities	160,344	15,946	15,070	14,417	14,259	14,010	14,149	14,504	14,632	14,207	14,400	14,750
White	109,228	10,850	10,165	9,830	9,650	9,539	9,635	9,849	9,988	9,666	9,875	10,184
Black	22,304	2,124	2,029	1,944	2,020	1,981	1,995	2,088	2,055	2,007	1,996	2,065
Other	31,224	2,975	2,993	2,897	2,848	2,855	2,828	2,807	2,758	2,771	2,759	2,733

Based on OPTN Data as of March 5, 2017

### Organ Donor Need among African Americans

African Americans have a disproportionate need for donated organs due to increased prevalence of ESRD, yet donate less than their need. The U.S. population is 13% African American, and they represent 34% of those in need of kidney donation.<sup>16</sup> In 2016, African Americans represented 13.3% of all donors as compared to Whites who represented 68.0% of the donor pool (see Table 2).<sup>15</sup>

**Table 2: White and African American U.S. Organ Donors, 2016**

Donor Type	# of all donors	# of African American donors	African American % of all donors	# of White donors	White % of all donors
Living	5,975	554	9.3%	4,197	70.2%
Deceased	9,971	1,570	15.7%	6,653	67.7%
Total	15,946	2,124	13.3%	10,850	68.0%

Source: HRSA U.S. Organ Procurement and Transplantation Network (OPTN). Based on OPTN data as of February 12, 2017.

African Americans tend to donate at a rate on par with their proportion of the U.S. population, however there is still a gap between organ need and organs available for transplant. The ability to close this gap relies on there being a growing and genetically diverse organ donation pool, which must represent as broad of a cross-section of histocompatibility profiles from the population as possible.<sup>17</sup> Due to the heterogeneity that exists among African Americans within

their histocompatibility antigens, antigen-matched organs for their transplantations are scarce.<sup>18</sup> Thus, their underrepresentation in the donor pool makes finding organ matches challenging.

### **Barriers to Organ Donation among African Americans**

There are several barriers to African American organ donation that have been identified in the research literature. According to Callender and Miles, obstacles to donation include lack of awareness, religious beliefs, fear of premature death after signing a donor card, fear of racism, and distrust of the medical community.<sup>19</sup> Per a qualitative study conducted by Shilling et al., transcripts revealed several additional perceived barriers to kidney donation among African Americans such as pre-existing medical conditions, financial concerns, and fear of surgery.<sup>20</sup> Other barriers based on literature are costs associated with donation, unwillingness to donate, medical comorbid conditions, loss to follow-up, and poor coping mechanisms.<sup>21</sup>

Many African Americans are unaware of the need and the benefits of organ donation. A study conducted by Creecy and Wright reported that African Americans were more willing to consider donation if they were aware of another African American who had received an organ transplant.<sup>22</sup> The National Minority Organ Tissue Transplant Education Program (MOTTEP) sought to reduce the lack of awareness by educating minority communities on facts about organ transplants by encouraging family discussions about donations; encouraging minorities to participate in organ transplantation endeavors; and by promoting the self-maintenance of kidneys, livers, hearts, lungs and other organs.<sup>19</sup>

Religious beliefs are also a consideration regarding organ donation for many African Americans as they play a prominent role in African American communities and culture.<sup>23</sup> Research suggests that willingness to donate is inversely associated with the perceived importance of spirituality and religion.<sup>24</sup> Though many Western religions approve of organ donation, there

still remain questions as to whether one's particular religion supports it, and there are still beliefs that in order to transition into the afterlife that the body must remain intact.<sup>25</sup>

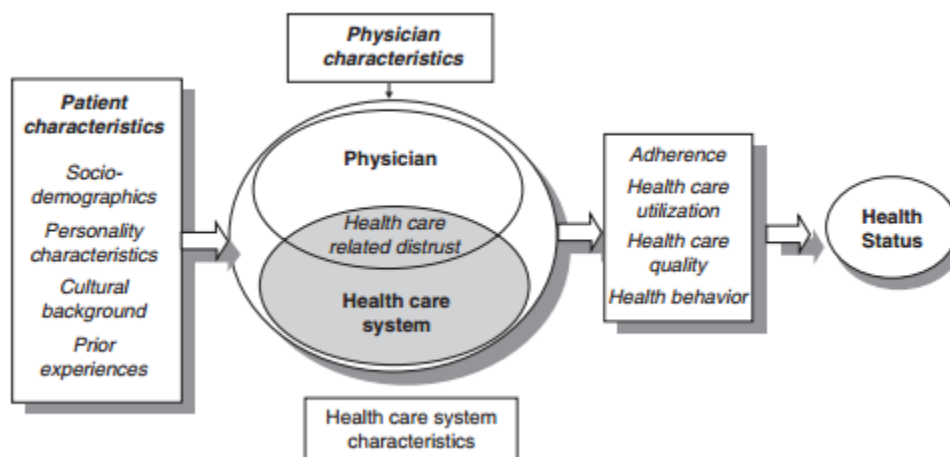
Fear also seems to be a major deterrent for African Americans to become organ donors. Fear of surgery and fear of body mutilation are specific areas that have been expressed.<sup>21</sup> There is much in the literature that relates to African American fear of donation, and many of the fears seem to relate to the distrust many have of the health care system based on historical experiences. One consistent fear among African Americans is the belief that if they consent to organ donation health care providers will do less to save their lives.<sup>26</sup> They also questioned the intentions of medical professionals as to whether they were concerned about their safety or whether they were "just after the organs."<sup>20</sup> Lastly, they also felt that they would receive poor quality of care due to the racism that is believed to be held by many medical professionals.<sup>27</sup> These barriers and fears culminate into a general feeling of distrust for the health care system and tends to influence the decision of African Americans to become organ donors.

The need for organ donation in the African American community must be addressed by understanding the contributing factors to the behavior. Individually-oriented behavior change strategies oftentimes support a victim-blaming ideology that ignores the social causation of disease.<sup>28,29</sup> It is important to understand the relationship between distrust and health behaviors by using a framework to study the pathways linking distrust to actual health behavior. Therefore, this literature review will focus on the relationship between health care system distrust and the decision to donate cadaveric organs among African Americans using an adapted version of the Conceptual Model of Health Care Distrust developed by Armstrong.<sup>30</sup>

## Theoretical framework

This work is guided by an adapted version of the Conceptual Model of Health Care Distrust (see Figure 1).<sup>30</sup> According to Armstrong, the model demonstrates how the pathways between patient characteristics, such as socio-demographics, personality characteristics, culture, and prior experiences lead to health care related distrust, and furthermore, how these pathways lead to health behaviors and eventually health status.<sup>30</sup> This is important because patients who have a higher level of health care related distrust are less likely to seek health care or to adhere to health care recommendations.<sup>30</sup> Per the model, health care related distrust is segmented into physician distrust and health care system distrust. However, this thesis will focus on the pathway between distrust in the health care system and the related health behavior, which for the purposes of this work is defined as organ donation. Guided by the Conceptual Model of Health Care Distrust<sup>30</sup>, three factors of health care distrust will be discussed: distrust in the health care system, distrust in medical professionals, and distrust in the organ allocation system.

**Figure 1: Conceptual Model of Health Care Distrust, Armstrong, 2005**



## **Research Aims**

This thesis will focus on the pathways between health care system related distrust and health behavior. For the purposes of this comprehensive literature review health behavior is defined as organ donation. These pathways were examined by reviewing the literature for empirical studies that focused on this association. The research questions that guided this review were:

- What is the association between African American distrust of the health care system and the decision to donate cadaveric organs?
- What is the association between African American distrust of medical professionals and the decision to donate cadaveric organs?
- What is the association between African American distrust of the organ allocation system and the decision to donate cadaveric organs?

The aim of this work is to review empirical studies to understand the relationship between African American distrust in the health care system and the decision to donate organs. Using the Conceptual Model of Health Care Distrust as a guide, we will review the pathways of how these factors of distrust may potentially affect African American health behaviors.

## Chapter Two – Literature Review

There are several barriers to African American donation, with distrust in the health care system standing out as a prominent one. Using the Conceptual Model of Health Care Distrust as a guide, this section will review literature with the aim of studying the relationship between African American distrust in the health care system as a whole. Next this chapter will present a review of medical experimentation on Blacks and African Americans; and how these experiences may influence the decision to donate organs.

### African American Distrust in the United States Health Care System

Distrust is defined as *no* trust or confidence in, according to Merriam-Webster online. This is not to be confused with mistrust, which is defined as a *lack* of confidence. In many texts distrust and mistrust are used interchangeably, but for African Americans, because of experiences within the U.S. health care system, it is more appropriately defined as having no confidence (distrust) since many do not believe that the health care system treats them with the same dignity and respect as it does others.<sup>31</sup>

Even today, African Americans are still skeptical and continue not to trust the medical community. According to a study of 173 African Americans surveyed in a northeastern urban community, only 22% indicated a trust for doctors and the medical system, with the lack of trust being greatest among 25 to 35 year olds.<sup>32</sup> This is important to organ donation in that trust in the medical system is believed to be critical in the decision to donate organs. Of those who said that they did not trust physicians and the medical system, 46% indicated that they would not donate organs.<sup>32</sup>



Health care distrust is commonly cited as an important contributor to racial disparities in health and health care, following the argument that higher distrust among racial minorities interferes with them seeking medical care and with their adherence to medical recommendations.<sup>33,34</sup> Armstrong's study of health care system distrust reported that 20% to 80% of African American participants reported feelings of distrust, and that this distrust was strongly associated with self-reported fair and poor health.<sup>34</sup> In this same study, African Americans tended to have higher levels of distrust within certain components of the health care system than other ethnic groups. One example of significance was medical research. The study also reported that African Americans had a higher distrust of hospitals than Whites.<sup>34</sup> A potential reason for these outcomes is that the history of medical racism in the U.S., particularly around medical research and clinical care has created deep-rooted suspicion about the motives of the health care system.<sup>34</sup> Reviewing this history may inform future decisions related to improving inequalities related to health care.

Medical research and clinical trials are important for the advancement of healthcare discovery and should ideally be representative of the population. The National Institutes of Health (NIH) Revitalization Act of 1993 mandated the inclusion of minorities and women in clinical trials<sup>35</sup>, however African American participation continues to be disproportionately low. One study examined the differences between social distrust and interpersonal distrust among African Americans and Whites to see whether past personal experiences or the views of society at large affected participation. Based on this study, African Americans expressed higher levels of societal distrust in clinical research than Whites.<sup>34</sup> African Americans did not believe that their physician would fully explain research participation<sup>31</sup>, felt that physicians would treat them like guinea pigs, and whether intentional or not, would treat them differently than White patients.<sup>31</sup>

These feelings of distrust are the crux of the issue. Although African Americans require more health care services due to increased risk factors, medical racism and structural racism reduce access to health care services. This finding is consistent with the decision not to donate organs due to negative societal pressures regarding the historical and current treatment of African Americans within the medical system. According to a 2012 study conducted by Russell et al., African Americans who were found to have high levels of cultural distrust, defined as the extent to which African Americans trust Whites, were less willing to consent to organ donation or permit the recovery of organs from family members.<sup>36</sup>

### **Medical Experimentation on African Americans**

African American distrust in the health care system is likely rooted in histories of medical experimentation on African Americans. Many advances in the medical community owe their successes to the unethical treatment of Black slaves. They were often used for medical demonstrations, including operating amphitheaters, classroom or bedside demonstrations, and experimental facilities.<sup>37</sup> Dr. J. Marion Sims, known as the Father of Gynecology perfected the surgical procedure for the cure of vesico-vaginal fistula experimenting on seven Black enslaved women over a period of four years.<sup>38</sup> None of these women volunteered for the procedures or gave consent. One of the women nearly lost her life when Sims used a sponge to remove the urine from her bladder.<sup>39</sup> Sims was successful in the repair after performing thirteen operations on a slave woman named Anarcha. Anarcha endured each of these operations without anesthesia in a makeshift hospital in his backyard.<sup>39</sup>

Also in the same era, several other physicians gained notoriety by African American slave experimentation. Dr. Crawford Long who is celebrated for being the first physician to use ether as a general anesthetic, used slaves for many of his earlier trials.<sup>40,41</sup> Dr. Thomas Hamilton was a

physician-planter who was trying to find the best remedies for heat stroke by experimenting on African American slaves. To test his medicines, he dug a hole in the ground and heated it with fire to high temperatures. He used a slave named Fed to ingest various homemade medicines and to sit naked in the heated fire pit to see how much heat his body could withstand before eventually passing out due to heat and exhaustion. Hamilton continued his works on the same slave by blistering his skin and purposely bleeding him to “ascertain how deep [his] Black skin went”.<sup>37</sup>

In the early 1950’s, an African American woman named Henrietta Lacks visited Johns Hopkins Hospital for cervical cancer treatment. The cancer was uncontrollable and she died shortly thereafter; however, at her death, tissue from her cancerous tumors were given to a researcher named George Otto Gey who cultured the cells and created what is called the HeLa cell line. This cell line has been instrumental in the development of the polio vaccine, cancer research, AIDS, gene mapping and other scientific research.<sup>42</sup> Though Ms. Lacks’ cells were famous in the scientific world it must be noted that no one, including Ms. Lacks gave permission for her cells to be used. Her family only found out that her cells were used 20 years after her death. They receive no financial benefit for the scientific usage of her cells<sup>43</sup> though the medical industry has profited billions.

Another prominent example is the Tuskegee Syphilis Study began in Macon County, Alabama in 1932 as a study to “determine the natural course of untreated, latent syphilis in Black males.”<sup>44</sup> This study proceeded for 40 years and was sanctioned and supported by the Federal government. By the time that the study ended, over 600 African American men had been involved under false pretense that they were being treated.<sup>44</sup> The conclusion of the Tuskegee Syphilis Study in 1973 is an example of the past and current beliefs that African Americans are marginally human, therefore, regular codes of ethics were not applicable. As stated by Brandt, “The Tuskegee Study

reveals the persistence of beliefs within the medical profession about the nature of Blacks.”<sup>44</sup> It is these beliefs that create skepticism among African Americans and the hesitation to participate in standard systems of care.

The unethical treatment of African Americans may not be as overt as those just reviewed; however, it still occurs in many ways. According to a study by the University of Virginia, 50% of White medical students and residents believe that “Blacks age more slowly than Whites; their nerve endings are less sensitive than Whites’; their blood coagulates more quickly than Whites’; [and that] their skin is thicker than Whites.”<sup>45</sup> The University of Virginia study “highlights how a confluence of mistaken attitudes about race, biology and pain can flourish in one of the worst possible places: medical schools where the future gatekeepers of relief are trained.”<sup>45</sup> These prior experiences of racial discrimination are strongly associated with both health care distrust and race.<sup>46</sup> As health care distrust is a factor of racial disparities in health and health care, these experiences of medical racism further reduce the likelihood that African Americans will trust the medical community enough to become organ donors.

### **African American Decisions to Donate Organs**

The Conceptual Model of Health Care Distrust hypothesizes that distrust in the health care system potentially affects medical adherence, health care utilization, the quality of health care received, and health behavior.<sup>30</sup> Based on literature, trust in the health care system varies in the way it is associated with organ donation<sup>47</sup> and it is a critical factor as to whether African Americans elect to donate.<sup>27,47</sup>

The distrust that African Americans commonly have for the health care system has been a factor in their rate of donation. African Americans donate at rates lower than other ethnic groups<sup>9</sup> and at rates lower than their need<sup>6</sup>; and based on the model, addressing and reducing health care

distrust will need to be considered in order to positively influence their decision.<sup>34</sup> An increase in the African American donor pool can satisfy a serious need and lead to more positive health outcomes.

An increasingly large number of studies explore the issue of the relationship between health care related distrust and the decision to donate organs, however, there needs to be a comprehensive review to summarize the findings across the studies. This thesis intends to contribute to the evidence base by providing a summary of those relating to the pathways of health care distrust and the decision to donate organs among African Americans.

## Chapter Three - Methods

This section details how the literature was selected, the research design used, the data collection instrument used, and how the selected studies were analyzed.

### Research Design

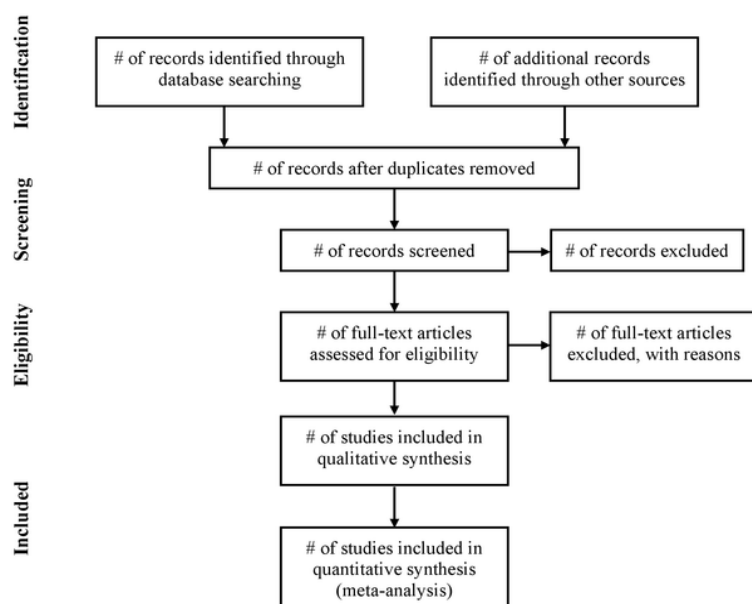
The research design employed for this work is a comprehensive literature review. A comprehensive literature review was selected to provide an assessment of the current state of African American donation trends and to identify key questions to prompt additional research on the topic. This type of review and synthesis across studies is particularly useful for planning future intervention studies.<sup>48</sup> Comprehensive literature reviews are useful for informing policy decisions because they span across several studies as opposed to focusing on one single study. However, a few limitations of comprehensive literature reviews are that the researcher must use studies conducted by others without clear knowledge of methods and data quality, and the review is bound by existing literature which may be outdated.

The comprehensive literature review was conducted by adapting the stages as described by the Thomas G. Carpenter Library<sup>48</sup>:

1. Selecting databases
2. Formulating an effective search strategy
3. Locating the materials and composing the review
4. Updating the initial search

In addition to the literature review stages, an adapted version of the PRISMA guidelines were used. The PRISMA guidelines provided a methodology to inform stage three of the Cochrane five stages. The PRISMA methodology gave a means to identify, screen, determine eligibility, and decide whether particular studies should be included within the review (see Figure 2).<sup>49</sup>

**Figure 2. Flow of information through the different phases of a systematic review**



## Target Population

Publications about the relationship between African American distrust in the health care system and the decision to donate organs were researched and reviewed. Only U.S. based empirical studies published between the years of 1990 and 2015 were included. The studies were required to have a minimum of 15% self-identified African American participants and a focus on organ donation. The minimum inclusion percentage was selected to ensure a reasonable amount of African American participation. Studies that focused on blood and tissue donation were excluded. The publications were selected based on topic relevance and relation to the adapted Conceptual Model of Health Care Distrust.<sup>30</sup>

## Procedures

Multiple searches were conducted during August 2016 and March 2017. Information about the topic of study was found using multiple methods of research and included publications dating from 1990 to 2015. The articles used were from a collection of electronic search engines such as

Pubmed, Medline, and PsycINFO. These databases were searched rigorously to obtain relevant peer reviewed publications and articles. Research was also conducted by consulting the references of reviewed literature and by using web engine searches such as Google and Bing to obtain data for African American health and donor totals and trends. The keywords that were used to conduct the searches are summarized below, (see Table 3). These broad terms were selected based on topic relevance and their ability to generate a comprehensive pool of possible studies.

**Table 3. Search key words**

	<b>African American distrust in the health care system and the effects on organ donation</b>
<b>Key Words</b>	organ, trust, Black; organ, trust, African American; organ donation African American trust

Three databases were searched and initially yielded 218 publications. The review was conducted in two stages. Stage One: Abstracts, methods and discussions were read and assessed for relevance. Stage Two: If the publications met the test of relevance they were retained for a complete read and inventoried into a spreadsheet within an Excel workbook. The spreadsheet represented information related to the research question.

Upon review, 175 publications were found to be duplicates and were removed, leaving 43 publications to be screened according to the inclusion criteria noted in Table 4.



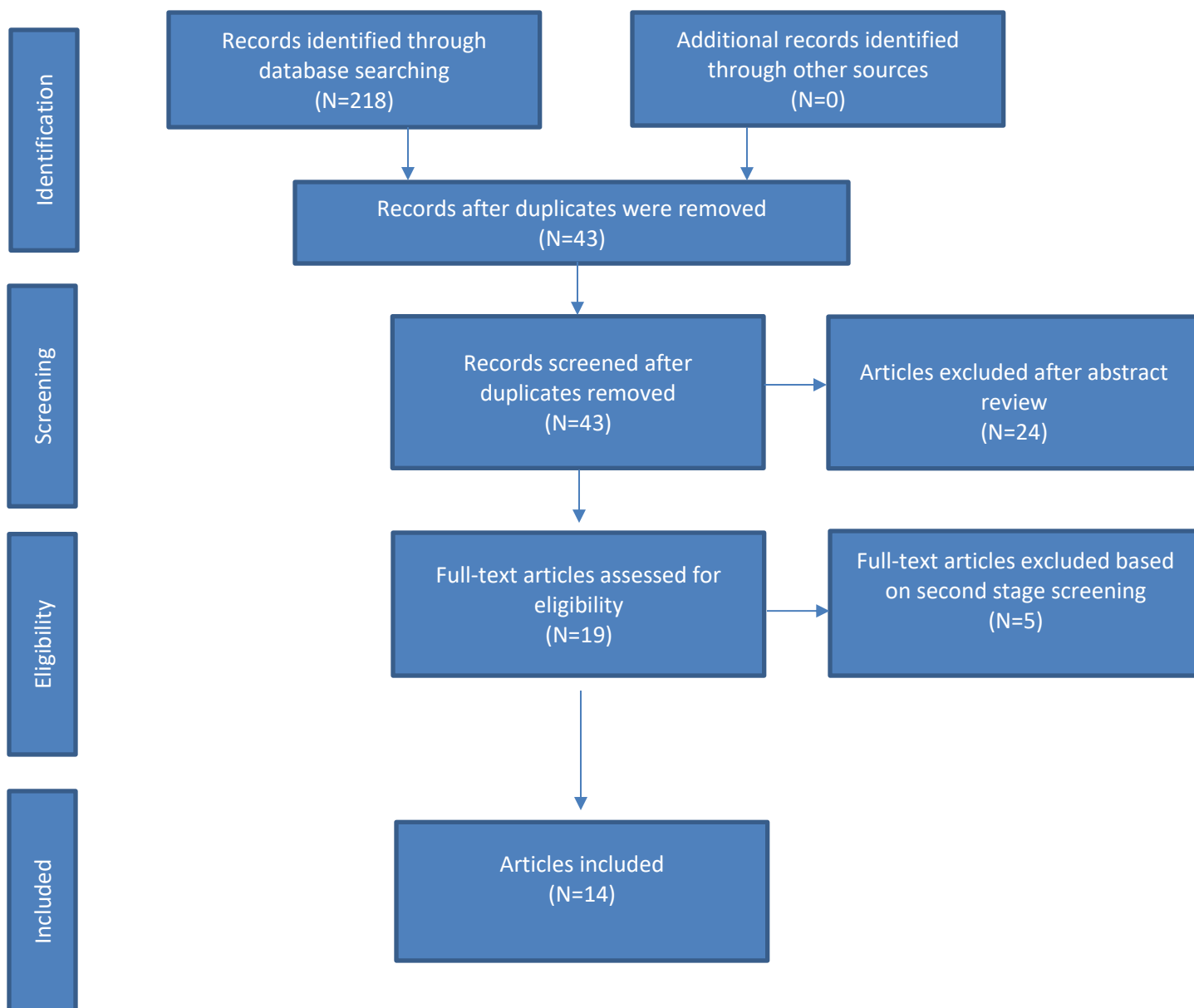
**Table 4. Inclusion criteria**

Inclusion Criteria	
1.	Date: Information published no earlier than 1990.
2.	Peer reviewed, empirical study.
3.	Study sample must have included at least 15% African Americans.
4.	Study must have been conducted in the U.S.

Publication titles, abstracts, methods and result sections were reviewed and an additional 24 were excluded. Studies were excluded if they: were not empirical studies; were not based in the U.S.; did not have at least 15% African American participation; focused on living donation, blood, or tissue donation; did not study the relationship between distrust in the health care system and the decision to donate organs. Publications were then read completely, resulting in an additional five being excluded because they did not have a focus on health care distrust and African American organ donation. No publications were added from other sources and the final result was 14 articles included for review (see Figure 3).<sup>50</sup>

The remaining publications were reviewed for areas of distrust relating to the association of health care distrust and African American decision to donate organs. Publications were then categorized into three areas of distrust guided by the Conceptual Model of Health Care Distrust<sup>30</sup>: distrust of the health care system, distrust of medical professionals, and distrust of the organ allocation system.

**Figure 3. Diagram illustrating the identification, screening, eligibility and inclusion of articles to literature review**



## Chapter Four - Results

This section discusses the findings from the literature search and analysis. Fourteen publications were reviewed and analyzed based on inclusion criteria (see Appendix 1). All 14 studies focused on cadaveric organ donation intentions, donation attitudes, and/or willingness; one publication focusing on cadaveric brain donation intentions (see Table 5). Based on the research questions and guided by the theoretical model, the publications were categorized into distrust of the health care system (N=8), distrust of medical professionals (N=8), and distrust of the organ allocation system (N=3). Four of the fourteen publications were related to one of more of areas of distrust; therefore studies could contribute to more than one research question. The results concluded that there was a relationship between distrust of the health care system, distrust of medical professionals, and distrust of the allocation system and the decision to donate organs among African Americans. There were three studies Robinson et al. (2015)<sup>51</sup>, Russell et al. (2012)<sup>36</sup>, Jefferson et al. (2011)<sup>52</sup> that found no association between distrust in the health care system and the decision to donate organs among African Americans.

**Table 5: Literature Summary by Research Question Study Findings**

	<b>Studies that found an association</b>	<b>Studies that found no association</b>
<b>What is the association between African American distrust in the health care system and the decision to donate cadaveric organs? (N=8)</b>	Boulware et al. (2002) Minniefield et al. (2001) Minniefield (2002) Morgan (2008) Robinson et al. (2015) Russell et al. (2012) <sup>1</sup> Siminoff et al. (2006)	Robinson et al. (2015) Russell et al. (2012) <sup>2</sup> Jefferson et al. (2011)
<b>What is the association between African American</b>	Brown (2012) Creedy et al. (1990)	

<sup>1</sup> Russell et al.'s study showed an association between distrust in the health care system and the decision to donate organ among verbal intentions.

<sup>2</sup> Russell et al.'s study showed no association between distrust in the health care system and the decision to donate organ among written intentions.

	<b>Studies that found an association</b>	<b>Studies that found no association</b>
<b>distrust in medical professionals and the decision to donate cadaveric organs? (N=8)</b>	DuBois et al. (2009) Minniefield (2002) Morgan (2006) Morgan et al. (2008) Purnell et al. (2011) Robinson et al. (2015)	
<b>What is the association between African American distrust in the organ allocation system and the decision to donate cadaveric organs? (N=3)</b>	Morgan et al. (2008) Robinson et al. (2012) Siminoff et al. (2006)	

### **Distrust of the Health Care System**

Distrust of the health care system was a common among African Americans in the publications reviewed. Eight of the fourteen studies concluded that this distrust was significantly associated with whether African Americans decided to donate cadaveric organs. Minniefield's study of an African American community in Buffalo, New York<sup>32</sup> found that trust in the health care system was crucial in the decision to donate organs, 46% of those indicating distrust in the health care system communicated that they would not donate. A study of sample that included 41.6% African Americans living in Metropolitan Baltimore, Maryland found that this distrust explained a 4% to 7% decrease in African Americans' willingness to donate organs compared to Whites.<sup>24</sup>

Brown's study of African American participants sought to study general areas of reluctance to donate organs based on lack of trust and other factors. Most participants reported having some reservations about organ donation, and that their reservations were related to their distrust of the health care system, with nearly 60% agreeing that health care distrust was strongly associated with organ donation.<sup>27</sup> In addition to the distrust, it was further explained by 24% of the study sample

fearing that being an African American organ donor minimized their chances of survival should there be an accident or if they became chronically ill.<sup>27</sup>

Other studies concluded that African American distrust of hospitals and the health care system varied in the association with the decision to donate. Minniefield's study, which comprised of 28% African American, compared general attitudes concerning the issue of organ donation and found that 38% of African Americans indicated that they would not be willing to donate compared to 10% of Whites due to reasons such as "if I am an organ donor, I won't get the necessary medical attention", and "personal reasons."<sup>47</sup>

The variation in the relationship between health care system distrust and the decision to donate also included two publications indicating that health care system distrust was not associated with the decision to donate organs. Jefferson et al.'s study of 464 elderly participants (21% African American) from the Alzheimer's Disease Core Center found that less than 50% of African American elders consented to donating their brain to research, compared to 75% of White elders.<sup>52</sup> However, the study found no association between health care system distrust and consent to donation among African Americans. Similarly, Robinson et al.'s study explored donation-related knowledge, attitudes, beliefs and distrust also found that general trust in the health care system was not associated with the decision to donate, but that varying dimensions of trust function differently in how attitudes toward donation are influenced.<sup>51</sup> Lastly, based on Russell et al.'s study of the association between distrust in the health care system and African American donation intentions, there was also not a significant association found in African Americans' distrust in the health care system and written donation intentions.<sup>36</sup>

## **Distrust of Medical Professionals**

The literature suggests that African Americans' negative attitudes about organ donation based on personal experiences, as well as negative subjective norms, shaped their intentions to donate.<sup>36</sup> Feelings that doctors would not take care to save them, or medical abandonment; knowledge about unethical government sanctioned medical experiments, as well as present day experiences with medical racism, created an atmosphere of distrust of medical professionals.<sup>36</sup>

Eight of the fourteen publications suggested a relationship between physician distrust and organ donation among African Americans. Each of the eight publications cited that trust in physicians is an important factor in the decision to donate. Of the 70 African Americans studied (29% of the study sample), Brown concluded that approximately 60% agreed that mistrust of medical professionals is strongly associated with organ donation<sup>27</sup>; African Americans and Hispanics were more concerned than Whites that if they signed a donor card and their heart stopped beating, physicians would do less to save their lives.<sup>26</sup>

The belief that medical professionals would not do everything in their power to save them was consistent throughout reviewed publications. Purnell et al.'s study of the racial and ethnic differences in U.S. donor designation found of those African Americans surveyed (17% of the study sample) who had not designated their organ donation status were found to be significantly less likely than Whites to trust that their physicians would put their medical needs above all other considerations.<sup>53</sup> Brown's study concluded that African Americans are concerned about racism in the medical profession and that this racism will negatively impact the quality of care that they can or will deliver.<sup>27</sup> African Americans' lack of confidence in medical professionals affects their willingness to consider organ donation. In a study of all African American participants, lack of

confidence in medical professionals was found to be significantly associated with donation-related attitudes and beliefs.<sup>22</sup>

### **Distrust of the Organ Allocation System**

General distrust in the health care system as it relates to the organ donation system was also apparent in African Americans' decisions to donate. Three of the fourteen publications found that African Americans did not trust the organ allocation process and per Minniefield's study of 173 African Americans, participants felt that organs would be given to select people.<sup>32</sup> Another study found that African Americans were also more likely than Whites to want to know that the organs they give go to a same race recipient.<sup>54</sup> A study analyzing the reasons people decide to sign donor cards found that it was largely based on religion and the desire to help others, however the reasons cited for choosing not to sign were a mistrust of doctors, hospitals and the organ allocation system, as well as a belief in a U.S. black market for organs.<sup>55</sup> This lack of trust in such a critical facet of the organ donation process has been found to be fundamental in shaping donation attitudes, intentions and behavior.<sup>56</sup>

## Chapter Five - Discussion

### Summary of Study

The goal of this study was to complete a comprehensive review of literature related to distrust in the U.S. health care system, distrust in the medical profession, and distrust in the organ allocation system and the decision to donate organs among African Americans. Guided by the Conceptual Model of Health Care Distrust, and based on inclusion and exclusion criteria, a total of 14 empirical studies were reviewed and analyzed in relation to the research questions. Articles were not segmented exclusively into categories, and as a result, many applied to more than one research question. The final breakdown was as follows: eight publications applied to distrust in the health care system, eight publications applied to distrust in the medical profession, and three publications applied to distrust in the organ allocation system. All 14 publications focused on cadaveric donation intentions and whether overall health care distrust was a factor in their decision by using quantitative questionnaires and surveys. All publications were based in the U.S. and had study samples of at least 15% participants who self-identified as African American.

The collection of articles that focused on overall health care system distrust and the decision to donate organs among African Americans suggests that historical and current medical experiences affect whether African Americans are willing to donate organs. The cultural narrative born by decades of unethical treatment within the clinical and health care systems have made it challenging for many African Americans to believe that they will be treated the same as others or that they will receive the same access to health services.<sup>47,57</sup>

Similarly, the relationship between African American distrust in medical professionals in many cases is a strong factor as to whether African Americans will decide to donate organs.<sup>26</sup> There is a vulnerability necessary to seek medical treatment and to adhere to recommendations of care. When trust is not present with physicians or those who deliver care it is difficult for one to



believe that their best interest will be prioritized. The literature reviewed suggests that an improvement in developing and rebuilding trust within these relationships is foundational to improving the state of African American organ donation.

Lastly, it was generally suggested that feelings of distrust in the organ allocation system also prevents many African Americans from donating organs.<sup>51</sup> Many question the fairness of the system and whether African Americans have equal access to donated organs. One potential solution would be to improve the transparency of the allocation process and to demonstrate that organs are given and/or procured based on availability and need regardless of race or ethnicity.

### **Limitations**

The comprehensive literature reviewed studies that explored feelings of African American distrust of the U.S. health care system and how it affects their decision to donate organs; however, as with most studies, there were several limitations to the review. First, the number of studies reviewed was small, in that only fourteen publications met the inclusion criteria and were included for review. This may limit the generalization of findings to the larger African American population. Secondly, no rigorous method was used to assess the quality of studies, which could potentially impact the quality of conclusions. Lastly, due to the need to have a reasonable number of studies to include in the comprehensive literature review, studies that included at least 15% of self-identified African Americans in the U.S. were included and reviewed. This may also raise questions about the applicability of findings to African Americans in general since some of the studies had fewer proportions of African Americans.

### **Implications**

This comprehensive literature review offered an opportunity to synthesize empirical studies relating to African American donation by analyzing the pathways from health care system

distrust to health behavior. The implications of this study for public health is a greater understanding around African American health care distrust as it relates to the decision to donate organs. African Americans die at a greater rate from diseases where organ donation could provide a life-saving option. Obtaining a greater understanding of factors that contribute to African American distrust could potentially offer health educators and health program designers the insight to develop programs to address these areas, and positively affect the knowledge, attitudes, and interest of potential African American donors to increase the African American organ donor pool.

### **Recommendations for Future Research and Conclusion**

Many factors have contributed to the distrust African Americans express about the health care system and how this distrust affects the decision to donate organs. A history of unethical treatment, medical racism, and medical disparities have led to skepticism about health care facilities, health care professionals, and the organ allocation system. More research is needed to gain a deeper understanding of specific experiences African Americans have encountered that may have created opinions and social norms around organ donation. For example, studies that explore whether there is a linkage between African American positive or negative experiences with the health care system and health care distrust and how this may be related to organ donation behavior. Another example could be, one on one interviews with African Americans from varying ages, education, and socioeconomic backgrounds to offer insight into factors that inform these views and to present data for systemic change. Lastly, studies should be conducted using larger samples of African Americans since many of the sample sizes were small and differed across studies. It is important to acknowledge that many of these areas of distrust are deeply rooted and may not be easily overcome, however a greater understanding of the factors that influence behaviors may show progress towards addressing the issue and increasing the African American donor pool.

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## Appendix 1

### Literature Matrix

	Reference	Study Sample	Purpose	Study Location	Methods	Key Points about Health Care Distrust and Decision to Donate Organs	Limitations	Measure of Distrust/Outcome	Distrust Categories
1.	Boulware EL, Lloyd RE. Understanding disparities in donor behavior: race and gender differences in willingness to donate blood and cadaveric organs. Medical Care.2002;40(2):85-95	N=385; 41.6% AA (n=114 AA Females, n=46 AA Males)  Adults (18-75)	To assess race and gender differences in willingness to donate blood and cadaveric organs, and to determine the extent to which several factors (including sociodemographic characteristics and attitude about religion and mistrust of hospitals) might explain differences in willingness to donate.	Baltimore, Maryland, metropolitan area	Cross-sectional telephone survey	When researchers adjusted the statistical model for respondents' mistrust of hospitals and concerns about discrimination in hospitals it explained a 4% to 7% difference in willingness to donate for AA females and AA males when compared to white males.	Sample may not be generalizable to the entire United States population, also only Black and White ethnic groups were included for study.	Distrust was assessed based on the level of agreement with statements adapted from the Medical Mistrust Index.  Donor identification on Drivers License.	Health care system
2.	Brown ER. African American present perceptions of organ donation: a pilot	N=70: 100% AA	To explore 5 general areas of reluctance	U.S., state unknown	Quantitative and qualitative survey	Most participants reported	None expressed.	Participants were asked to answer 9 quantitative	Medical profession



	Reference	Study Sample	Purpose	Study Location	Methods	Key Points about Health Care Distrust and Decision to Donate Organs	Limitations	Measure of Distrust/Outcome	Distrust Categories
	study. ABNF J. 2012 Spring;23(2):29-33.	Assumed adults	associated with organ donation among AAs (lack of awareness, lack of trust by medical professions, fear of premature death, discrimination, religious beliefs and misconceptions)			having some reservation concerning organ donation, and many of them reported that their reservations were related to their mistrust of the medical profession; there is a concern of racism, believed to be held by some medical professionals, which negatively impacts the quality of care delivered; 59.26% agreed that mistrust of the medical profession is a reason strongly associated with organ donation;		questions indicating their agreement or disagreement on a 5-point Likert scale, with a tenth open-ended question for them to input comment.  No donor outcomes specified.	

	Reference	Study Sample	Purpose	Study Location	Methods	Key Points about Health Care Distrust and Decision to Donate Organs	Limitations	Measure of Distrust/Outcome	Distrust Categories
						23.64% agreed that being an organ donor minimizes AAs chances of survival should there be an accident or if they become chronically ill.			
3.	Creecy RF, Wright R. Correlates of willingness to consider organ donation among Blacks. Soc Sci Med. 1990;31(11):1229-32.	N=217, 100% AA  Adults (18-64)	To examine and assess correlates of willingness to consider organ donation within a Black population.	Southeastern U.S.	Survey/questionnaire	Among attitude-belief variables, the willingness to consider donation was significantly associated confidence in medical doctors.	None expressed.	The independent variable that measured confidence in medical doctors was determined by asking "What do you think doctors would do if you were hospitalized with a life threatening injury and the doctors knew you were an organ donor?" The coded responses were 1 for 'do everything possible to save	Medical profession

	Reference	Study Sample	Purpose	Study Location	Methods	Key Points about Health Care Distrust and Decision to Donate Organs	Limitations	Measure of Distrust/Outcome	Distrust Categories
								my life' and 0 for 'let me die so that my organs can be donated'.  Written donation intentions.	
4.	DuBois JM; Waterman AD; Iltis A; Anderson Is rapid organ recovery a good idea? An exploratory study of the public's knowledge and attitudes. J. American Journal of Transplantation. 9(10):2392-9, 2009 Oct. [Journal Article. Research Support, Non-U.S. Gov't] UI: 19681823	N=70 community members; 29% AA, n=20  Adults	To learn what the public thinks about ROR (Rapid Organ Recovery)	St. Louis, MO	Survey/questionnaire	African-American and Latino participants expressed greater fears than Caucasians that if they consented to organ donation, physicians might do less to save their life; In pre-focus group survey, compared to Caucasians and Hispanics, AAs were significantly	The sample size was local, small, and 63% female, therefore it may not be generalizable.	Distrust was measured by asking participants "if I sign my donor card, I fear that physicians might do less to save my life if my heart unexpectedly stops beating. Response choices were "agree", "unsure", or "disagree".  Written intentions on a donor card.	Medical profession

	Reference	Study Sample	Purpose	Study Location	Methods	Key Points about Health Care Distrust and Decision to Donate Organs	Limitations	Measure of Distrust/Outcome	Distrust Categories
						less likely to believe that healthcare providers should do more to increase the number of organs available (65% agreed vs 72% white, 92% Latinos); Both AAs and Hispanics were also more concerned that if they signed their donor card and their heart stopped beating, physicians would do less to save their life.			
5.	Jefferson AL, Lambe S, Cook E, Pimontel M, Palmisano J, Chaisson C. Factors associated with	233 participants from the Alzheimer'	To examine factors associated with brain donation	Boston University Alzheimer's Disease	Survey/questionnaire	Logistic regression model found no significant	Insufficient power to detect possible	AAs only completed a cultural mistrust inventory, and all	Health care system

	Reference	Study Sample	Purpose	Study Location	Methods	Key Points about Health Care Distrust and Decision to Donate Organs	Limitations	Measure of Distrust/Outcome	Distrust Categories
	African American and white elders' participation in a brain donation program. Alzheimer Dis Assoc Disord. 2011 Jan-Mar;25(1):11-6. doi: 10.1097/WAD.0b013e3181f3e059.	s Disease Core Center (ADCC) research registry. 21% of survey respondents were AA, n=49  Adults >65	program participation among AAs and white elders.	Core Center		predictor, trust in healthcare institutions for brain donation status among AA respondents.	effects, particularly among AAs, limitations inherent to survey research.	participants completed the Healthcare Systems Distrust Scale, which measured attitudes toward the healthcare system, including competence, confidentiality, honesty, and fidelity and beliefs about healthcare practices and health system motives. Scores ranged from 10(low levels of distrust) to 50 (high levels of distrust)  No donor outcomes specified.	
6.	Minniefield WJ, Multiple. Organ donation survey results of a Buffalo, New York, African-American	N=173; 100% AA	To evaluate general patterns of attitudes	AA community	8-question voluntary survey	Overall trust for doctors and the medical system was	None expressed.	t-test to evaluate the difference of continuous	Medical profession / Health

	Reference	Study Sample	Purpose	Study Location	Methods	Key Points about Health Care Distrust and Decision to Donate Organs	Limitations	Measure of Distrust/Outcome	Distrust Categories
	community. J Natl Med Assoc. 2002 Nov;94(11):979-86.	Adults 18 and older	relating to organ donation based on age and educational levels.	in Buffalo, NY		found to be low among the sample. 34% indicated a lack of trust for doctors and the medical system, with 44% indicating that they somewhat trusted doctors and the medical system. Only 22% indicated a trust for doctors and medical system. The lack of trust was found to be greater among the 25 to 35 year olds. Trust for doctors and the medical system appeared to be crucial with respect to the likelihood of		variables between different groups.  Written donor intentions.	care system

	Reference	Study Sample	Purpose	Study Location	Methods	Key Points about Health Care Distrust and Decision to Donate Organs	Limitations	Measure of Distrust/Outcome	Distrust Categories
						donating organs. Of those who said that they did not trust doctors and the medical system, 46% indicated that they would not donate, and 34% indicated that they might donate. There were no gender, age, or educational patterns for trust or distrust of doctors.			
7.	Minniefield WJ, Yang J, Muti P. Differences in attitudes toward organ donation among African Americans and whites in the United States. J Natl Med Assoc. 2001 Oct;93(10):372-9.	N=892; 28% AA, n=249  Adults	To compare general attitudes between AAs, white, and other minorities concerning the issue of organ donation and to identify the	Six cities in the United States: Detroit, Michigan; Jacksonville and Tampa, FL;	Survey/questionnaire	The results suggest that distrust in the healthcare system varied in the way that it is associated with donation intentions. 38% of AAs	None expressed.	t-test to evaluate the difference of continuous variables between different groups.  Written donor intentions.	Health care system

	Reference	Study Sample	Purpose	Study Location	Methods	Key Points about Health Care Distrust and Decision to Donate Organs	Limitations	Measure of Distrust/Outcome	Distrust Categories
			factors that hamper AAs from becoming donors.	Atlanta, GA; Hammond, Indiana; and Buffalo, NY		indicated that they would not donate organs, compared to 10% of whites. Top reasons listed were "personal reasons" and "if I am an organ donor I won't get the necessary medical attention". AA were more concerned about getting proper medical treatment than whites. 46% of AA expressed a lack of trust for doctors.			
8.	Morgan SE, Harrison TR, Afifi WA, Long SD, Stephenson MT. In their own words: the reasons why people will (not) sign an organ donor card. Health	N=78 family-pair dyads; 16.7% AA: n=11 dyads	To give a forum for and study the naturalistic conversation between family	Midsized southern state university	Multisite, qualitative survey	The study revealed reasons for not wanting to donate organs were mistrust	The study allows family members to spend more time	Transcribed verbal data were entered into Ethnograph for coding and analysis.	Medical profession / Health care system/ Organ



	Reference	Study Sample	Purpose	Study Location	Methods	Key Points about Health Care Distrust and Decision to Donate Organs	Limitations	Measure of Distrust/Outcome	Distrust Categories
	Commun. 2008;23(1):23-33. doi: 10.1080/10410230701805158.	were AA, n=1 dyad was AA and white, n=1 dyad was AA and Latino  Adults (18-67)	members about their donation intentions.			of doctors, hospitals, and the organ allocation system and a belief in a Black market for organs in the U.S..	discussing organ donation than would be expected under normal circumstances; participants knew their discussions were being recorded so this may have created a certain level of consciousness.	Frequencies were assessed for codes to establish themes.  Verbal donor intentions.	allocation system
9.	Morgan SE. Many facets of reluctance: African Americans and the decision (not) to donate organs. J Natl Med Assoc. 2006 May;98(5):695-703.	N=310 AA adult members of the NAACP; 100% AA	To use theory to assess AAs attitudes and beliefs about their willingness to donate organs using the Organ	New Jersey	Survey/questionnaire	AAs who were lower in medical mistrust were more likely to have signed a donor card.	Study is not representative of AAs due to sample size. Sample was skewed towards more	Medical mistrust was measured using a five-item scale adapted from La Veist, Nickerson and Bowie. Respondents were asked:	Medical profession

	Reference	Study Sample	Purpose	Study Location	Methods	Key Points about Health Care Distrust and Decision to Donate Organs	Limitations	Measure of Distrust/Outcome	Distrust Categories
		Adults	Donation Model				educated, higher-income AAs. The medical mistrust scale had poor reliability. It was the first test of this scale with AAs.	"Whether they believe that doctors always try to act in the patients' best interest, whether they trust doctors, whether medical procedures are done on people without their consent, and whether doctors could be trusted to save their lives in the event of an emergency.  Written donor intentions.	
10	Purnell TS, Powe NR, Troll MU, Wang NY, LaVeist TA, Boulware LE. Donor designation: racial and ethnic differences in U.S. non designators' preferred methods for disclosing intent to donate organs. <i>Transpl Int.</i> 2011 Oct;24(10):999-	N=307 U.S. Adults who had not yet designated their donation intentions via drivers'	To assess the association of medical distrust on organ donation preferences to disclose intent to donate.	In four U.S. census divisions	National cross-sectional study of U.S. adults, aged 18-75 years. 20-minute telephone questionnaire was administered in	AAs who were nondesignators ' were statistically significantly less likely than whites to completely or mostly trust their	Participants who are willing to respond to a lengthy questionnaire may be different from those not willing to	Participants were asked questions to assess mistrustful attitudes regarding medical establishment by asking their	Medical profession

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	1007. doi: 10.1111/j.1432-2277.2011.01301.x.	licenses or organ donor cards (non designators); 17% AA, n=53  Adults			both English and Spanish.	physicians to put their medical needs above all other considerations. AAs were also statistically significantly less likely than Hispanics and whites to completely or mostly believe that when a person who is an organ donor becomes sick, doctors will try everything to save his or her life before removing organs.	participant in the study; participant behaviors assessed a one point in time may not predict future behaviors; results may not be generalizable	agreements with statements such as "I trust hospitals to put my medical needs above all other considerations" , and "I trust physicians to put my medical needs above all other considerations" . Possible responses included "completely agree", "mostly agree", "somewhat agree", "agree a little", or "not at all".  Verbal and written donor intentions.	

	Reference	Study Sample	Purpose	Study Location	Methods	Key Points about Health Care Distrust and Decision to Donate Organs	Limitations	Measure of Distrust/Outcome	Distrust Categories
11	Robinson DH, Perryman JP, Thompson NJ, Amaral S, Arriola KR. Testing the utility of a modified organ donation model among African American adults. J BehavMed. 2012 Jun;35(3):364-74. doi: 10.1007/s10865-011-9363-3.	N=585; 85.2% AA, n=499  Adults (19-96)	Explores the ways in which knowledge, trust in the donation/allocation process, and religious beliefs impact AA donation making.	Atlanta metropolitan area	Survey/questionnaire	The study sought to test a modified version of Morgan and Miller's Organ Donation Model. It explored trust in the donation/allocation process and religious beliefs impacts AA's donation decision making. Trust in the process of organ donation and allocation are associated with attitudes, which are associated with donation intentions.	Selection bias may be a concern.	Trust in the allocation system was measured using a 6-item scale that examine attitudes about the examination and racism within the allocation system. They indicated their agreement with the statements using a 5-point scale from 1 (strongly disagree) to 5 (strongly agree) - higher scores indicate greater trust in the organ allocation system.  Written donor intentions	Organ allocation system

	Reference	Study Sample	Purpose	Study Location	Methods	Key Points about Health Care Distrust and Decision to Donate Organs	Limitations	Measure of Distrust/Outcome	Distrust Categories
12	Robinson DH, Perryman JP, Thompson NJ, Lamonte Powell C, Jacob Arriola KR. Exploring Donation-related Knowledge Attitudes, Beliefs and Distrust Among African Americans. J Natl Med Assoc. 2015 Mar;107(3):42-50. doi: 10.1016/S0027-9684(15)30050-X.	N=585; 85.2% AA, n=499  Adults (19-96)	To understand barriers to AA donation to develop culturally-sensitive interventions that shape AAs' attitudes and donation intentions.	Atlanta metropolitan area	Educational sessions: videos, study, and questionnaire	The study found that varying dimensions of trust function differently in their influence on attitudes toward donation. Physician trust had the strongest relationship with attitudes toward donation and general trust in the healthcare system was not at all associated.	The AA participants may have been more homogenous with respect to their thoughts and feelings regarding organ donation.	Trust in the health care system was measured using a 5-item scale that measured attitudes regarding the existence of discrimination and racism with the health care setting. They indicated their agreement with the statements using a 5-point scale from 1 (strongly disagree) to 5 (strongly agree) - higher scores indicated more trust of the health care system. Physician trust was measured using a 3-item scale that measures the level of trust that participants have in physicians.	Medical profession / Health care system

	Reference	Study Sample	Purpose	Study Location	Methods	Key Points about Health Care Distrust and Decision to Donate Organs	Limitations	Measure of Distrust/Outcome	Distrust Categories
								No donor outcomes specified.	
13	Russell E, Robinson DH, Thompson NJ, Perryman JP, Arriola KR. Distrust in the healthcare system and organ donation intentions among African Americans. J Community Health. 2012 Feb;37(1):40-7. doi: 10.1007/s10900-011-9413-3.	N=585; 85.2% AA, n=499  Adults (18 years or older)	To study the association between distrust in the healthcare system and written and verbal expressions of donation intentions among AAs.	Atlanta metropolitan area	Cross-sectional research design	Health care system distrust was significantly associated with verbal donation intentions. No significant association was found between distrust in the health care system and written donation intention.	Study sample was skewed towards more educated, higher income AA women; it is possible that different results may have been obtained from another sample; cross-sectional attainment of written and verbal donation intentions limits the ability to rule out unintentional and	5-point scale on distrust in the healthcare system and donation intentions previously used in health research. The scale examined participant attitudes regarding the existence of discrimination and racism within health care settings.  Written and verbal donor intentions.	Health care system

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							unmeasured variable influences.		
14	Siminoff LA, Burant CJ, Ibrahim SA. Racial disparities in preferences and perceptions regarding organ donation. J Gen Intern Med. 2006 Sep;21(9):995-1000.	N=1283; 24% AA, n=312  Adults (18 years or older)	To identify reasons for lower organ donation rates by AAs by examining knowledge and attitudes about brain death, donation, and transplantation and trust in the healthcare system.	Ohio	Focus groups	AAs are less willing to donate their own or a family member's organs. They are half as likely to have signed a donor card and less likely to be willing to donate their own or a loved one's organs. AA express greater concerns about the trustworthiness of the healthcare system, both in general and in terms of the donation systems	Responses to projective questions are subject to a certain amount of inaccuracy. Social desirability may have affected people's responses.	Trust in the Health Care System scale was measured by 4-point Likert scale  Written intentions.	Healthcare system/ Organ allocation system

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						<p>specifically and were more likely to want to see the organs that they give go to other AAs. AAs were supportive of incentives for donation, especially to help with funeral expenses for the donor. The findings indicate that the inequalities experienced by AAs in their overall dealings with the healthcare system might negatively affect AAs willingness to donate organs.</p>			