Distribution Agreement

In presenting this thesis or dissertation as a partial fulfillment of the requirements for an advanced degree from Emory University, I hereby grant to Emory University and its agents the non-exclusive license to archive, make accessible, and display my thesis or dissertation in whole or in part in all forms of media, now or hereafter known, including display on the world wide web. I understand that I may select some access restrictions as part of the online submission of this thesis or dissertation. I retain all ownership rights to the copyright of the thesis or dissertation. I also retain the right to use in future works (such as articles or books) all or part of this thesis or dissertation.

Signature:

_____ _____

Briana M. Lucido Date

Understanding the Role of Social Norms in Organ Donation Decision Making Among African American Adults

By

Briana M. Lucido
MPH

Behavioral Sciences and Health Education

_____

Kimberly R. Jacob Arriola, PhD, MPH
Committee Chair

_____

Jennie P. Perryman, PhD, RN
Committee Member

_____

Colleen McBride, PhD, MA
Department Chair

Understanding the Role of Social Norms in Organ Donation Decision Making Among African American Adults

By

Briana M. Lucido

Bachelor of Arts, Sociology
University of Michigan
2013

Thesis Committee Chair: Kimberly R. 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 Behavioral Sciences and Health Education
2015

Abstract

Understanding the Role of Social Norms in Organ Donation Decision Making
Among African American Adults
By Briana M. Lucido

BACKGROUND:
African Americans (AAs) comprise a disproportionate number of patients waiting on the national transplant list, but are underrepresented among registered organ donors. While barriers to organ donation are well understood, little research explores factors that facilitate interest in donation. Because AAs are oftentimes characterized by strong extended relationships and shared decision making, social norms may be an influential factor in donation intentions and behavior. Utilizing the Theory of Reasoned Action, this study demonstrated the application of theory to better understand the role social norms play in donation decision making, among AAs.

METHODS:
Self-administered questionnaires were completed by 425 AA adults residing in the metropolitan Atlanta area. Social norms were measured using a Likert scale consisting of two items that addressed the perceptions on levels of favorability of donation and levels of influence a loved one has over the participant's donation decision making. Main outcomes assessed were donation intentions and expression of donation intentions via designation on one's driver's license.

RESULTS:
Logistic regression results indicate that a loved one's level of favorability of donation is associated with both donation intentions (OR=2.14, $p \leq 0.01$) and expression of donation intentions (OR=1.71, $p \leq 0.01$); however findings approached significance with the level of influence a loved one has on donation intentions (OR=1.47, $p=0.07$) and was not associated with expression of donation intentions (OR=1.07, $p>0.05$).

CONCLUSION:
Findings suggest that a loved one's level of favorability impacts donation decision making, and conversely, that a loved one's level of influence does not impact donation decision making. Future research should consider exploring these relationships further to understand how social norms can facilitate or inhibit AAs from becoming organ donors. Thus, focusing on social norms and encouraging communication may prove to be useful means of future interventions to improve engagement in donation among AAs.

Understanding the Role of Social Norms in Organ Donation Decision Making Among African American Adults

By

Briana M. Lucido

Bachelor of Arts, Sociology
University of Michigan
2013

Thesis Committee Chair: Kimberly R. Jacob Arriola, PhD, MPH

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 Behavioral Sciences and Health Education
2015

Acknowledgements

I would like to thank my thesis committee chair, Dr. Kimberly R. Jacob Arriola, and my committee member, Dr. Jennie P. Perryman for the opportunity to work with them on this research. Your support, guidance, and assistance throughout the process helped me immensely. I greatly appreciate all the time and dedication you put into mentoring me throughout this project.

Thank you also to Dr. Nancy Thompson and Dana Robinson. Your infinite assistance and confidence in me throughout this process meant a lot to me.

Further, this project would not have been complete without the love and encouragement from my family and friends. I am so grateful to have such wonderful people in my life who believe in me and in the work I can accomplish.

Table of Contents

Tables and Figures

Figures:

Tables:

Chapter One: Introduction

Organ Transplantation in the United States

Organ transplantation is a preferred treatment option for many individuals with end-stage organ failure. Organ transplantation is a procedure that surgically implants a donated organ into a patient who is suffering from end-stage organ failure (U.S. Department of Health and Human Services, 2014a). Patients who meet all the medical, social, and financial criteria for a transplant are placed on the national organ transplant waiting list (United Network for Organ Sharing, 2013). On average, one patient is added to the national transplant waiting list every 10 minutes (U.S. Department of Health and Human Services, 2014f). Once a person is added to the national transplant waiting list, he or she can wait anywhere from a few hours to a few years to receive an organ transplant. The wait time for a transplant varies due to a variety of factors, including what organ or organs the patient is in need of, how sick the patient is, how well the donor organs medically match with the patient, and how many organs are available in a given area (United Network for Organ Sharing, 2013).

Currently, over 120,000 Americans are on the national transplant waiting list to receive an organ (United Network for Organ Sharing, 2014c). In the state of Georgia, there are over 5,000 individuals on the national transplant waiting list (Organ Procurement and Transplantation Network, 2015b). The organs in highest demand, both in the United States and in Georgia are kidney, liver, and heart (Organ Procurement and Transplantation Network, 2014a; Organ Procurement and Transplantation Network, 2014b). An average of 79 individuals receive an organ transplant every day (U.S.

Department of Health and Human Services, 2014f). But despite this average, about 18 individuals on the national transplant waiting list die each day waiting for a transplant (U.S. Department of Health and Human Services, 2014f). While organs are in great demand for the life saving opportunity they offer through organ transplantation, organs are also scarce resources due to the shortage of donated organs.

While the majority of organ donations occur after the donor has died, some organs can be donated while the donor is alive (U.S. Department of Health and Human Services, 2015a). Deceased donors can give their kidneys, pancreas, liver, lungs, heart, and intestines, while living donors can provide a kidney, or a portion of their liver, lung, or intestine (U.S. Department of Health and Human Services, 2015b). Although living donation is growing in necessity as an alternative to deceased donation, the current study pertains only to deceased donation.

Need for Organ Donors

While the demand for organs is increasing, there continues to be a substantial gap between the number of organs needed and the number of organs donated. To decrease the number of deaths of individuals waiting on the national transplant waiting list, and increase the number of transplants performed, an increase in the number of organs donated is necessary. One way to achieve this is to increase the number of individuals who designate themselves to serve as donors after their death. Individuals of all ages, races, ethnicities, and geographic locations have the opportunity to become registered donors. Individuals can communicate their desire to be a donor through various means such as, signing up on their state's donor registry, carrying a donor card, indicating their

decision to be a deceased donor on their driver's license, and talking with their family and friends about their wishes to be a donor (U.S. Department of Health and Human Services, 2014c). By becoming a donor, one can save as many as eight lives though organ donation and enhance the lives of many others through tissue donation (U.S. Department of Health and Human Services, 2014e).

Additionally, diversity in donors is necessary. Donated organs are matched to potential recipients based on a wide variety of criteria, therefore a greater diversity of donors can increase access to organ transplantation for those in need (U.S. Department of Health and Human Services, 2014f). Accordingly, there is a great need for deceased donors from all racial and ethnic groups. But, while the proportion of deceased donors by racial and ethnic group is similar to the racial and ethnic makeup of the United States population, some groups, particularly racial and ethnic minorities are in greater need of a transplant (U.S. Department of Health and Human Services, 2014f).

Transplantation Need among Racial and Ethnic Minorities

In 2013, less than about 40.0% of the United States population identified themselves as belonging to a racial or ethnic minority group (U.S. Census Bureau, 2014). Yet, racial and ethnic minorities represent over half of the individuals on the national transplant waiting list. The ethnic breakdown of waitlist candidates is found to be as follows: 42.7% Caucasians, 30.0% African Americans (AAs), 18.7% Hispanics/Latinos, 7.0% Asians, 1.1% Native Americans and Alaskan Natives, 0.5% Native Hawaiians and other Pacific Islanders, and 0.5% Multiracial (U.S. Department of Health and Human Services, 2014b). The disproportionate number of racial and ethnic minorities on the

national transplant waiting list is in part due to various health issues these groups suffer from, which can cause organ failure and the need for a transplant. For example, compared to Caucasians, racial and ethnic minorities including AAs, Asians, Native Hawaiians and other Pacific Islanders, and Hispanics/Latinos are more likely to suffer from high blood pressure and diabetes, both of which can damage the kidneys and lead to the need for a kidney transplant (U.S. Department of Health and Human Services, 2014f).

Transplantation and Donation Rates among AAs

On the national transplant waiting list AAs comprise a disproportionate number of individuals waiting for a transplant. Specifically, AAs account for the second largest racial group on the national transplant waiting list and the largest minority group in need of a transplant (Organ Procurement and Transplantation Network, 2015a; U.S. Department of Health and Human Services, 2014b). Additionally, almost 35.0% of individuals waiting for a kidney transplant are AA (U.S. Department of Health and Human Services, 2014f).

While AAs represent a large portion of those on the national transplant waiting list, there continues to be low numbers of AAs who donate their organs. In 2013, 17.0% of all deceased donors were AA (U.S. Department of Health and Human Services, 2014b). Although organs are not matched based on race or ethnicity, critical factors for matching a donor organ and a recipient are more likely to be found among individuals of the same race and ethnicity (U.S. Department of Health and Human Services, 2014d). Donors and recipients of different races and ethnicities are oftentimes found to be a match, however, the success of an organ transplant increases when organs are matched

between individuals of the same racial or ethnic background (Donate Life America, 2014). Thus, a more diverse group of donors from all racial and ethnic groups would contribute to a more heterogeneous donor pool, and would ultimately benefit AAs in need of a transplant (National Research Council, 1999a). Therefore, increasing donation rates among all racial and ethnic groups, particularly AAs, is of public health concern.

Barriers to Organ Donation among AAs

To increase the number of deceased donors, particularly among AAs, research has focused on exploring the various obstacles to donation (National Research Council, 1999b). A number of studies have investigated barriers to donation faced by AAs, to understand the reasons why donation rates among this population continue to be low. Results from these studies indicated the persistent barriers to donation reported among AAs include a lack of knowledge and awareness about donation, distrust in the healthcare system, religious beliefs, and low social support (Brown, 2012; Callender, Bayton, Yeager, & Clark, 1982; Arriola, Robinson, Perryman, & Thompson, 2008; McNamara et al., 1999; Minniefield, Yang, & Muti, 2001; Morgan, 2006; Morgan & Cannon, 2003; Morgan, Miller, & Arasaratnam, 2003; Park, Smith, & Yun, 2009; Russell, Robinson, Thompson, Perryman, & Arriola, 2012; Siminoff, Burant, & Ibrahim, 2006; Yuen et al., 1998). These barriers have been found to greatly influence the attitudes held by AAs regarding donation. Other studies have suggested that AAs and other racial minorities were approached less about deceased donation compared to Whites (Callender, Bayton, Yeager, & Clark, 1982; Goldberg, Halpern, & Reese, 2013; Guadagnoli et al., 1999; Minniefield et al., 2001). Overall, AAs have been found to have less positive attitudes

toward donation compared to Whites (Morgan et al., 2003; Park et al., 2009). With less positive attitudes and multiple barriers, it is clear why many AAs are reluctant to become deceased donors.

Increasing Organ Donation Rates among AAs

While barriers to donation among AAs are understood, little research has explored the factors that facilitate and support donation among this population. Further, there have been few intervention studies to help increase donation rates among AAs. Some programs have emerged, which aim to increase donation knowledge, intentions, and expression of intentions, among AAs (Callender, Hall, & Branch, 2001; Arriola, Robinson, Thompson, & Perryman, 2010; Arriola, Robinson, Perryman, Thompson, & Russell, 2013). But, more work focusing on breaking down these barriers and increasing donation rates is warranted, especially among AAs.

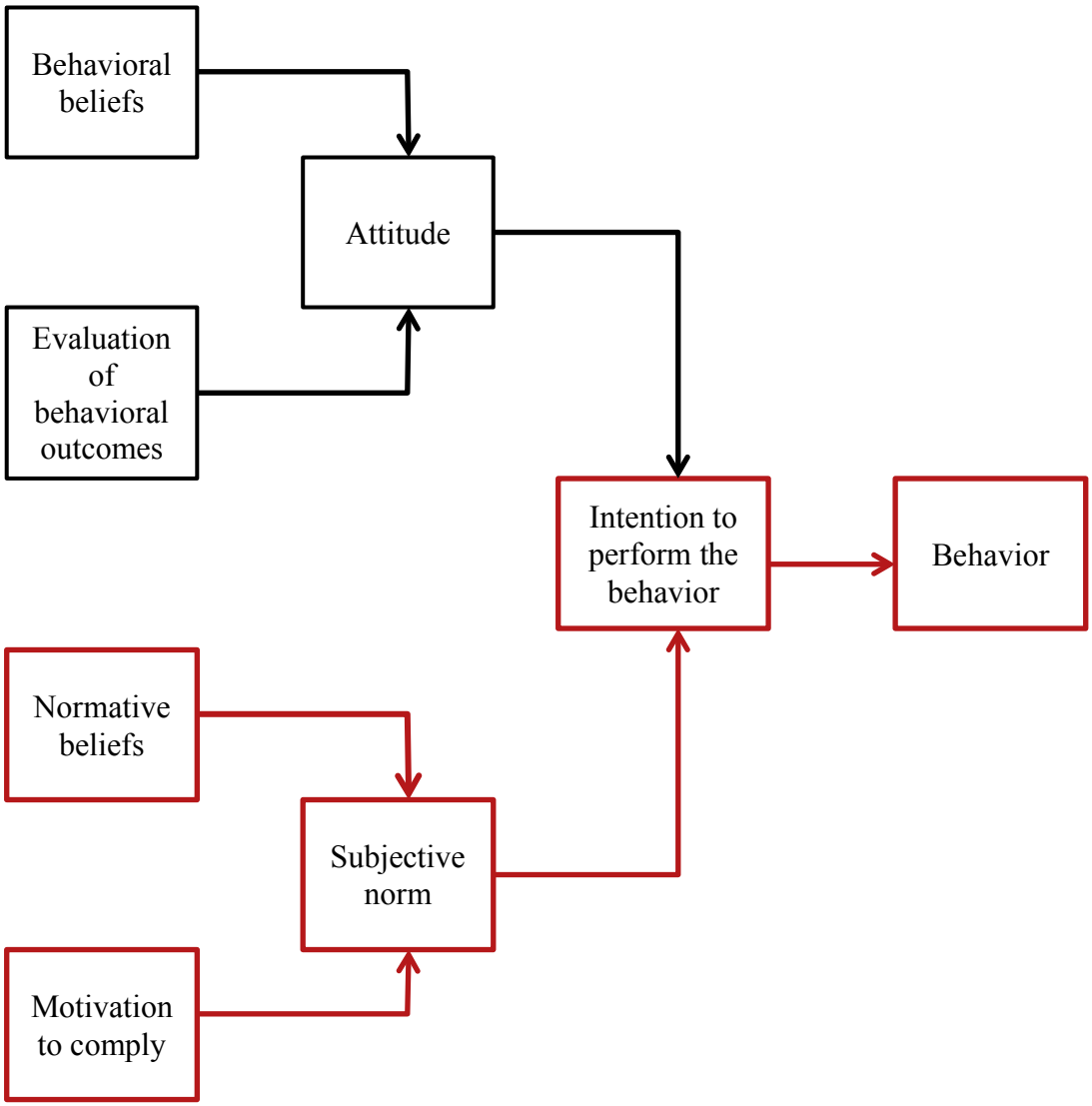
Of particular interest is the role and impact loved ones have in organ donation decision making among AAs. In general, AAs have been found more willing to donate their organs after death if they communicated and discussed these end-of-life arrangements with family members (McNamara et al., 1999). Further, family discussions have been found to be the most influential and important source of information about donation, compared to other information sources, such as church, work, Department of Motor Vehicles (DMV), television, and newspaper (Morgan & Cannon, 2003). Through family discussions, social norms about donation and transplantation are communicated and have been found to play an influential role in AA's intentions to donate (Morgan et al., 2003). Thus, due to the power of social norms, encouraging family discussions about

donation has been suggested (Morgan & Cannon, 2003). Unfortunately, little research has investigated social norms and their impact on AA's organ donation decision making, but such research could prove useful in increasing donation rates.

Theoretical Framework: Theory of Reasoned Action

This study was informed by the Theory of Reasoned Action (TRA), a framework developed by Icek Ajzen and Martin Fishbein. Ajzen and Fishbein argued that individuals think about the consequences or implications of their decisions, behaviors, and actions before participating in a particular behavior, hence the name "reasoned action" for this theoretical model (Ajzen & Fishbein, 1980). The goal of TRA is to explain behaviors of volition, or behaviors individuals engage in because they choose or desire to (Fishbein & Ajzen, 1975). The theory asserts that one's intentions to participate in volitional behaviors are influenced by one's attitudes and subjective norms (Ajzen, 1991). Organ donation is a voluntary behavior, and as such, many of the constructs of TRA can explain the facilitators and barriers to becoming a donor. The full TRA theoretical framework is displayed in Figure 1 below. Within this model, this study focused on the subjective norms pathway to intention to perform the behavior and the behavior itself.

Figure 1. The Theory of Reasoned Action



Within the TRA framework, behavioral intention is the most important indication of behavior (Ajzen, 1991; Montaño & Kasprzyk, 2008). Intention to perform a behavior is driven by subjective norms, often referred to as social norms, and attitude toward the behavior (Montaño & Kasprzyk, 2008). According to TRA, subjective norms are defined by normative beliefs, or whether important individuals in a person's life approve or

disprove of the particular behavior, and weighted by the person's motivation to comply with those important individuals in their life (Montaño & Kasprzyk, 2008). Thus, one's subjective norms toward a behavior result from the sum of their normative beliefs and motivation to comply (Montaño & Kasprzyk, 2008). Ultimately, subjective norms directly influence one's intentions to perform a behavior and impact one's behavior (Montaño & Kasprzyk, 2008).

In previous studies, TRA has been applied to donation (Brown, 2012; Morgan, 2006; Weber, Martin, Corrigan, & Members of COMM 160, 2007). Additionally, many studies have employed the Theory of Planned Behavior (TPB) when studying donation (Park et al., 2009). As an extension of TRA, TPB adds the construct of perceived behavioral control (PBC) over the behavior to the theoretical model (Montaño & Kasprzyk, 2008). Because many studies on donation have used both TRA and TPB, a review of the research that has applied either theory to the topic of donation was included for purposes of this study. But, because this study focused on the constructs of subjective norms, behavioral intention, and performing the behavior, TRA was chosen as the theoretical model.

In previous research, the application of TRA to donation has demonstrated strong associations between TRA constructs and organ donation decision making. One study compared intentions to enroll in the state organ donor registry and intentions to talk with family about donation across five different ethnic groups: Hispanic Americans, White Americans, AAs, Asian Americans, and Native Americans (Park et al., 2009). Results of this study indicated that AAs and Hispanic Americans did not differ from White Americans in intentions to enroll in the state organ donor registry, when controlling for

subjective norms, attitudes, and PBC (Park et al., 2009). On the other hand, Native Americans and Asian Americans displayed higher intentions to enroll in the state organ donor registry in comparison to White Americans, when controlling for the same constructs (Park et al., 2009). Additionally, in comparison to White Americans, Native Americans and Hispanic Americans did not differ in intentions to talk with family about donation, when controlling for subjective norms, attitudes, and PBC (Park et al., 2009). Further, AAs and Asian Americans demonstrated greater intentions to talk with family about donation, compared to White Americans, when controlling for the same constructs (Park et al., 2009). Overall results indicated that across all ethnicities, attitudes and subjective norms were significantly associated with intentions to enroll in the state donor registry, and that attitudes, subjective norms, and PBC were associated with intentions to talk with family about donation (Park et al., 2009).

Another study examined TRA's ability to predict the behavior of signing a donor card (Weber et al., 2007). Specifically, this study aimed to investigate how attitudes and subjective norms related to both intentions to sign a donor card and the behavior of signing a donor card, among college students (Weber et al., 2007). Results of this study indicated that intentions to sign a donor card were significantly positively associated to both attitudes and subjective norms towards signing a donor card (Weber et al., 2007). Further, authors found that those with more positive attitudes and normative beliefs were more likely to sign a donor card, and those who had greater intentions to sign a donor card, signed a donor card at higher rates (Weber et al., 2007).

Additionally, one study examined the many reasons why AAs decide not to donate organs and aimed to advance the development of a more comprehensive model for

reasons why AAs choose or choose not to donate organs (Morgan, 2006). This study indicated that traditional variables such as attitudes, knowledge, and social norms are most influential on decisions to donate, among AAs (Morgan, 2006). Again, these findings support the notion that the constructs within TRA, attitudes and subjective norms, influence intentions and behaviors around donation.

The use of TRA in these studies confirms the potential use of the theory in evaluating donation decision making, among AAs. Since the literature has illustrated how social norms are influential among AAs and little research has investigated the impact they have on donation decision making, TRA can help inform studies that explore how social norms impact intentions and behavior of becoming a donor, among AAs.

Research Questions

Utilizing TRA, the current study demonstrates the application of theory to better understand the role social norms play in organ donation decision making, among AAs. Specifically, this study sought to gain an understanding of how social norms impact donation intentions and expression of donation intentions via designation on one's driver's license, among AAs. Further, this study tested for moderation. The test of moderation explored whether the level of influence a loved one has over one's decisions about donation moderates the relationship between a loved one's level of favorability of donation and one's donation intentions. Additionally, a second moderation model was tested, using the same model, but with the second outcome of interest in this study, expression of donation intentions via designation on one's driver's license. The following research questions guided this study:

1. *What is the association between social norms and organ donation intentions, among AAs?*
2. *What is the association between social norms and expression of organ donation intentions via designation on one's driver's license, among AAs?*
3. *Does a loved one's level of influence over decisions about organ donation moderate the relationship between a loved one's level of favorability towards organ donation and one's organ donation decision making, among AAs?*

Due to the limited amount of research on the role social norms play in organ donation decision making, the present study was designed to gain knowledge in this area. Studying perceptions of a loved one's level of favorability of donation and level of influence over one's decision about donation, can provide insight on how social norms impact donation. Results of this study can help inform future research and interventions on donation and increasing the number of deceased donor registrants, among AAs.

Chapter Two: Literature Review

Organ transplantation has become an accepted treatment for those suffering from end-stage organ failure and, thus, increasing the need for organs and donors. The largest racial and ethnic minority group in need of transplants is AAs (U.S. Department of Health and Human Services, 2014f). Yet, AAs continue to demonstrate low donation rates. This disparity warrants attention, especially due to the life saving opportunities that come with donation.

Factors Influencing Organ Donation Decision Making

Extensive research has been conducted investigating the barriers to donation among AAs. Results from these studies have identified common prominent concerns within the AA community regarding donation. These barriers include a lack of knowledge and awareness about donation, distrust in the medical profession and the healthcare system, religious beliefs, and low levels of social support (Brown, 2012; Callender et al., 1982; Arriola et al., 2008; McNamara et al., 1999; Minniefield et al., 2001; Morgan, 2006; Morgan & Cannon, 2003; Morgan et al., 2003; Park et al., 2009; Russell et al., 2012; Siminoff et al., 2006; Yuen et al., 1998). But, many of these barriers to donation have also been found to be facilitators to donation, such as knowledge and religious beliefs (Arriola, Perryman, & Doldren, 2005; Arriola, Perryman, Doldren, Warren, & Robinson, 2007). Additionally, several of these barriers and facilitators suggest an influence of social norms and the importance of family discussions about

donation and decisions about donation (Brown, 2012; McNamara et al., 1999; Minniefield et al., 2001; Morgan, 2006; Morgan & Cannon, 2003; Morgan et al., 2003).

One of the initial studies on the barriers to donation among AAs was conducted in 1982, and was considered one of the first steps to answering the question of why Blacks donate their organs less frequently, particularly kidneys (Callender et al., 1982). The purpose of this pilot project was to explore the dimensions and attitudes of potential Black donors, by assessing and evaluating their reactions to certain situations and questions (Callender et al., 1982). Results showed that respondents were aware of kidney transplants and the need for them, but lacked knowledge about kidney transplants in general, stressing the need for education and better communication about transplantation (Callender et al., 1982).

In this same study, researchers found positive facilitators toward donation among participant responses, including a strong desire to help others and a sense of restitution (Callender et al., 1982). Further, several barriers toward donation surfaced as well, including religion or superstition (Callender et al., 1982). In general, respondents believed that their body needed to stay intact for life after death (Callender et al., 1982). Further, participants lacked trust in the medical system, had fears of being left vulnerable with only one kidney, and were concerned with the implications for cross-race transplants and preferred not to cross racial barriers when donating organs (Callender et al., 1982). Ultimately, the four main reasons that researchers found as to why Blacks donate at a lower rate compared to Whites, were (1) lack of knowledge, (2) religion, (3) fear of complications, and (4) lack of communication between patients and health providers (Callender et al., 1982).

Many studies and interventions have been conducted since this breakthrough study, aiming at assessing the barriers AAs face to donation and investigating ways to increase donation rates among AAs. A more recent study was conducted to explore if these same barriers to donation still exist, among AAs. Specifically, this study was designed to explore if the concerns about donation that AAs have identified in previous research continue to exist, and if they do, to what degree (Brown, 2012). Five general areas of reluctance were identified and investigated (Brown, 2012). These areas were, lack of awareness, lack of trust by medical profession, fear of premature death, discrimination, and religious beliefs and misconceptions (Brown, 2012). In this study, TRA was used as the conceptual framework, with the idea that when a person is faced with the opportunity to partake in a behavior, he or she will base their decision to participate based on perceived social norms (Brown, 2012).

Results from this study showed that these five areas of concern still exist, particularly a lack of trust in the medical system (Brown, 2012). Over half of the participants (59.3%), agreed or strongly agreed that the AA community does not trust the medical community (Brown, 2012). Further, about one-third (33.3%), of participants agreed or strongly agreed that family influences assist in their decision of whether to become a donor, suggesting that loved ones have some level of influence over donation decision making (Brown, 2012). This study demonstrated that several of the barriers that inhibit AAs from becoming donors, still exist today. A more detailed breakdown and discussion of each of the main barriers and facilitators to donation identified by AAs in previous research and studies, follows below.

Barriers and Facilitators to Organ Donation

Knowledge, attitudes, and awareness. One of the most frequently reported barriers to donation expressed by AAs is an absence of knowledge about the processes and procedures related to donation. Knowledge has been found to be a predictor of willingness to donate, with higher amounts of knowledge about donation equating to higher willingness to donate and support donation (McNamara et al., 1999). But, compared to European Americans, AAs have been found to have less knowledge about donation (Morgan et al., 2003). Further, compared to Whites and Hispanics, AAs have been found less likely to have knowledge about donating eyes and lungs (Yuen et al., 1998). One study indicated that AAs were aware of kidney transplants and the need for them, but lacked knowledge about kidney transplants in general (Callender et al., 1982). On the other hand, studies have suggested that those who had knowledge about the shortage of organs and the need among AAs, felt a sense of responsibility to become donors and express donation intentions (Arriola et al., 2005).

One study aimed to investigate the relationship between various types of knowledge related to donation and transplantation, and the expression of donation intentions through a driver's license, a donor card, and sharing intentions with family members (Arriola et al., 2008). Data for this study were collected through a survey completed by parishioners from 10 churches located in the metropolitan Atlanta area (Arriola et al., 2008). The survey covered topics including beliefs and attitudes about donation and transplantation, knowledge of the donation and transplantation system, intentions to donate, and demographic characteristics (Arriola et al., 2008). Results showed that 44.0% of respondents indicated donation intentions on driver's license,

18.0% of respondents carried a donor card, and 36.0% of respondents reported discussing donation intentions with family within the last six months (Arriola et al., 2008). Further, results indicated variability in terms of how different types of knowledge are associated with written (donor card or noted on license), and verbal (discussions with family), expressions of donation intentions (Arriola et al., 2008). Specifically, knowledge of the allocation system and personal knowledge of a transplant recipient were strongly associated with written expression of intentions (Arriola et al., 2008). Further, personal knowledge of a transplant recipient was also strongly associated with verbal expression of donation intentions (Arriola et al., 2008). Also, results showed that knowledge of a transplant recipient or knowledge of a person who has been on the transplant waiting list was related to an increased readiness to express intentions both in writing and verbally (Arriola et al., 2008). Thus, having someone in one's network who experienced transplantation first-hand, suggests how norms may play a role in decisions to donate.

Results from this same study also indicated that concerns about the fairness in the allocation system might be central to the decision to donate organs, among AAs (Arriola et al., 2008). Participants displayed substantial concern in the fairness of the allocation system (Arriola et al., 2008). But, those participants who had a better understanding of the system were found more willing to express written donation intentions (Arriola et al., 2008). Overall, knowledge of allocation system and knowledge of a recipient were significantly associated with expression of intentions (Arriola et al., 2008). This study suggests that both knowledge of someone personally, and having concern for the need for transplant and donation among others of the same race, are important aspects in the decision to become a donor, and indicate a social component associated with norms.

Distrust in the healthcare system. Another major barrier to donation reported by AAs is a lack of trust in the medical profession and the healthcare system. Among AAs, trust in the healthcare system is central in influencing donation intentions, attitudes, and behavior (Russell et al., 2012). Compared to Whites, AAs consistently express greater concern in the healthcare system, indicating a substantial lack of trust (Siminoff et al., 2006). Many studies have reported half to a majority of AA participants indicating some level of distrust in doctors and/or the medical system, and have determined this lack of trust to be a considerable barrier to donation among AAs and a norm within this community (Brown, 2012; Callender et al., 1982; Minniefield et al., 2001; Morgan, 2006; Morgan et al., 2003). Reasons for these high levels of distrust in the healthcare system have been attributed to historical racial discrimination and poor treatment by the medical field, and these concerns and fears are still very prominent today, influencing donation perceptions and decisions, among AAs (Brown, 2012).

One study explored the correlates relating to donation support among three ethnic groups, Whites, AAs, and Hispanics (McNamara et al., 1999). Telephone interviews were conducted, using a survey covering topics including beliefs, attitudes, and knowledge about donation (McNamara et al., 1999). Results of this study indicated that across all three ethnic groups, three factors were significantly positively correlated with willingness to donate (McNamara et al., 1999). These factors were, having a discussion about death arrangements with family, agreement with the statement ‘Doctors do all they can to save a life before pursuing donation,’ and concerns about body disfigurement (McNamara et al., 1999). Further, family discussions about death arrangements were associated with a

willingness to donate across all three ethnic groups (McNamara et al., 1999). However, less than 40.0% of all participants had discussed this topic with family members (McNamara et al., 1999).

Body disfigurement was found to be a major concern relative to donation, among AAs and Hispanics, compared to Whites (McNamara et al., 1999). Also, this study suggested that AAs were less willing to donate if they worked in a health care profession, compared to AAs who had not worked in a health care profession (McNamara et al., 1999). Minorities were also found less likely to endorse the belief of doctors doing everything they can to save a life before pursuing donation (McNamara et al., 1999). Findings from this study support other research in this area, that ethnic minorities are less supportive of donation, with main factors influencing these donation decisions including distrust in the medical system and body disfigurement concerns (McNamara et al., 1999).

Another study aimed to better understand the relationship between levels of distrust in the healthcare system and written and verbal expression of donation intentions, among AAs (Russell et al., 2012). This study hypothesized that distrust in the healthcare system would be significantly positively associated with both verbal and written donation intentions (Russell et al., 2012). Written intentions were classified as indicating donation wishes on a donor card or on driver's license, and verbal expression was indicated by communication with family members about donation intentions (Russell et al., 2012). Using a cross-sectional design, data were collected through employment of Community Health Workers (CWs) to recruit participants to complete a survey (Russell et al., 2012). Topics on the survey included distrust in the healthcare system, donation intentions, and demographics (Russell et al., 2012). From a sample of 585 participants, 42.9% of

participants had written donation intentions, either by a driver's license or a donor card, and 25.5% of participants had verbally expressed donation intentions with family members (Russell et al., 2012).

Results from this study also demonstrated that distrust in the healthcare system varies in the way it is associated with donation intentions (Russell et al., 2012). Further, findings indicated only significant associations between distrust in healthcare system and verbal expression of donation intentions, and not with written expression of intentions (Russell et al., 2012). Specifically, those with lower levels of distrust in the medical system were more likely to verbally express donation intentions with family members, compared to participants with higher levels of distrust in the medical system (Russell et al., 2012). Overall, individuals with lower levels of distrust in the healthcare system were more likely to communicate their donation intentions compared to individuals with higher levels of distrust in the healthcare system (Russell et al., 2012).

The purpose of another study was to examine the likelihood of family members being approached for deceased donation, by race of the patient. Further, this study investigated whether agreeing to donate differed by race (Guadagnoli et al., 1999). Data were collected from medically suitable for donation White and AA patients, who died between 1990 and 1993 at 112 hospitals throughout the United States (Guadagnoli et al., 1999). Medical suitability for deceased donation was defined as patients less than 71 years of age, not having any contraindications to donation, and meeting the medical criteria for brain death, or individuals who have no brain activity and cannot breathe on their own, which indicates death of a patient (Guadagnoli et al., 1999; U.S. Department of Health and Human Services, 2015c). This study focused on the patients with a next of

kin, who would be approached about donation (Guadagnoli et al., 1999). The two variables of interest were whether the patient's family was approached about donation and their responses to the inquiry (Guadagnoli et al., 1999).

Results of this study revealed that patient families were approached by hospital staff regarding donation about 73.0% of the time, out of a sample of 2202 White patients and 814 AA patients (Guadagnoli et al., 1999). However, families of AA patients were approached less frequently (67.0%), compared to families of White patients (79.0%) (Guadagnoli et al., 1999). Of all the families approached about donation, less than half (47.0%), agreed to donate an organ (Guadagnoli et al., 1999). Consistent with other findings, fewer families of AA patients agreed to donate (31.0%), compared to families of White patients (52.0%) (Guadagnoli et al., 1999). Overall, AA families were approached less frequently by hospital staff regarding donation and were less likely to agree to donation, compared to White families (Guadagnoli et al., 1999).

Another study explored the racial disparities in preferences and perceptions regarding donation (Siminoff et al., 2006). This study examined knowledge and attitudes about brain death, donation, and transplantation and trust in the health care system to identify reasons for low donation rates, among AAs (Siminoff et al., 2006). To collect data, a telephone delivered survey was used (Siminoff et al., 2006). This survey covered topics such as knowledge about donation, attitudes towards donation, trust in the healthcare system, demographic information, and willingness to donate, through indicators of signing a donor card or marking on a driver's license, verbally expressing a willingness to donate, and willingness to donate a loved one's organs (Siminoff et al., 2006).

Results of this study indicated that AAs were less likely to donate their own organs or a family member's organs, compared to Whites (Siminoff et al., 2006). Further, AAs were found to be half as likely to have signed a donor card compared to Whites (Siminoff et al., 2006). Participants were overall very concerned about who their organs would be given to, and would prefer to have their organs donated to other AAs (Siminoff et al., 2006). Further, compared to White participants, AAs expressed greater concern in the healthcare system, indicating a lack of trust, both in general and specifically in the donation system (Siminoff et al., 2006). Findings of this study indicate that the lack of trust in the healthcare system experienced by AAs may directly relate to their intentions toward donation and negatively affect their willingness to donate (Siminoff et al., 2006). These feelings of distrust in the medical system suggest the need to further understand the norms of the AA community, and how these norms may inhibit or facilitate donation decision making.

Religious beliefs. A third commonly reported barrier to donation among AAs involves religious beliefs. Religious beliefs have been found to be a predictor of donation intentions and associated with attitudes towards donation (Robinson, Perryman, Thompson, Amaral, & Arriola, 2012; Robinson, Klammer, Perryman, Thompson, & Arriola, 2014). Concerns about bodily integrity for heaven, not understanding religious beliefs and stances on donation, and breaking religious doctrine, have been frequently reported in studies, with regards to donation (Arriola et al., 2007; Morgan, 2006; Morgan & Cannon, 2003; Robinson et al., 2014). But, studies have also suggested that religion and religious beliefs can serve as facilitators for donation, among AAs. The desire to help

others by serving as a donor, has stood out in shaping donation decision making among AAs, and stems from religious beliefs and norms (Arriola et al., 2005). Further, the role of religious leaders and their potential to help increase donation rates has been investigated (Arriola et al., 2007).

Objectives of one study were to better understand the attitudes and beliefs toward organ and tissue donation among AA clergy, messages AA clergy provide to parishioners regarding organ and tissue donation, and how AA clergy perceive the role of the church and the pastor in donation education (Arriola et al., 2007). This study used qualitative methods to collect a rich understanding of the attitudes, beliefs, and experiences of AA clergy regarding organ and tissue donation (Arriola et al., 2007). Focus groups with 26 AA clergy, specifically ordained ministers, were conducted at seven Christian-based churches in the Atlanta area, with a questionnaire distributed to participants following the focus groups (Arriola et al., 2007).

Results showed that participants were overall supportive of organ and tissue donation, but had severe concerns about the inequalities of the system that influenced their own willingness to identify themselves as donors (Arriola et al., 2007). The clergy expressed several concerns about the unequal access to organs and transplantation AAs face, due to ethnicity and class-based discrimination (Arriola et al., 2007). Participants also acknowledged that religious misconceptions are a major barrier to organ and tissue donation, particularly the belief of keeping the physical body whole and not manipulated, to return to Heaven as God created man (Arriola et al., 2007). While the clergy discussed the numerous attempts to debunk these misconceptions and discontinue these biblical misunderstandings, these misconceptions seem to perpetuate with parishioners (Arriola et

al., 2007). Further, participants indicated that religious leadership has done an insufficient job at educating their parishioners about organ and tissue donation, partially due to their own lack of knowledge and understanding of the donation and transplantation system (Arriola et al., 2007). The clergy were found to allow the parishioners to arrive at their own decisions regarding donations with careful weighing of donation advantages along with concerns about system inequalities (Arriola et al., 2007).

Overall this study demonstrated that clergy and other religious leaders have the potential to influence their parishioners on religious topics through a variety of mediums, and thus, if taught about the stance their religious organization takes on donation and how to discuss this topic with parishioners, these individuals can be very useful for interventions (Arriola et al., 2007). Further, the results of this study indicate the important role that religious leaders and AA clergy can play in creating norms that can improve donation rates among AA parishioners.

One study proposed the use of an adapted Organ Donation Model to better understand the relationship between knowledge, trust in the donation/allocation process, and religious beliefs, with intentions to donation decision making among AAs (Robinson et al., 2012). Similar to past studies, willingness to serve as a donor was evaluated separately from interest in providing written documentation of donation intentions (Robinson et al., 2012). This study hypothesized that trust in the allocation system, greater knowledge related to donation, and religious beliefs supportive of donation would be associated with positive attitudes towards donation, positive attitudes towards donation would contribute to greater intentions to become a donor, and greater knowledge about donation would be related to greater intentions to become a donor

(Robinson et al., 2012). Results from this study confirmed that knowledge, trust in the donation/allocation system, and religious beliefs are associated with attitudes, which is in turn associated with donation intentions (Robinson et al., 2012). These results suggest that religious beliefs have an important role in shaping donation decisions, among AAs (Robinson et al., 2012).

Another study investigated the association between religious beliefs and religious involvement, with donation intentions, among AAs (Robinson et al., 2014). Similar to previous studies, willingness to serve as an organ donor was evaluated separately from interest in providing written documentation of donation decisions (Robinson et al., 2014). Hypotheses for this study included: religious service attendance would be negatively associated with willingness to serve as a donor and written expression of donation decisions, subjective religiosity would be negatively associated with willingness to serve as a donor and written expression of donation decisions, and religious norms would be positively associated with willingness to serve as a donor and written expression of donation decisions (Robinson et al., 2014). Among participants in this study, two-thirds were willing to donate their organs after death, and about 46.0% expressed written donation decisions via a driver's license or donor card (Robinson et al., 2014).

Results from this study indicate that religious norms were significantly negatively associated with written expression of donation decisions (Robinson et al., 2014). Other results from this study indicate that among the religious variables used, religious norms were the most powerful factor of both willingness to serve as an organ donor and written expression of donation decisions (Robinson et al., 2014). Also, among participants of this study, those who considered themselves religious were less likely to be willing to be a

donor (Robinson et al., 2014). Further, participants who were taught that donation went against their religion were found less willing to be donors (Robinson et al., 2014). These findings further emphasize the important role of religious beliefs in influencing donation intentions and decisions among AAs, and illuminate the need to collaborate with religious communities to educate AAs about donation (Robinson et al., 2014; Robinson et al., 2012).

Discussions with family members and social norms. A fourth barrier and facilitator of donation that has received little attention is the role of family discussions and social norms. While research has shown that family discussions about donation have influenced intentions to become donors, studies have suggested these discussions rarely occur (Brown, 2012; McNamara et al., 1999; Minniefield et al., 2001). Studies have also indicated that family discussions about donation are among the most influential source for donation information among AAs (Morgan & Cannon, 2003). Thus, encouraging family discussions about donation is necessary to help increase the number of registered donors (Morgan & Cannon, 2003). More research and studies investigating the impact of social norms and family discussions on donation decisions is warranted to better understand the potential role they can play in increasing donor rates, particularly among AAs. Studies that have begun to investigate family discussions and social norms in relation to donation should be used as a platform for further research.

One particular study investigated the similarities and differences among AAs and European American on their attitudes, knowledge, and willingness to communicate about donation (Morgan et al., 2003). This study aimed to investigate and compare AAs and

European Americans intentions to donate organs, and the common barriers and facilitators contributing to that decision including knowledge, attitudes, social normative support, talking with family members, altruism, and level of trust in medical system (Morgan et al., 2003). Results showed that AAs had significantly less positive attitudes towards donation, less trust in the medical system, perceived less social support for organ donation, and less willingness to talk to family members about their decision to donate (or not to donate), compared to European Americans (Morgan et al., 2003). Results also suggested that social norms play an even greater influential role among AAs in regards to intentions to donate, compared to European Americans (Morgan et al., 2003). Overall, this study indicated that AAs have less amount of knowledge about donation, less favorable attitudes towards donation, and less perceived social support for donation, compared to European Americans.

The goal of another study was to pinpoint donation misconceptions held by AAs, and determine which of these misconceptions are crucial factors in willingness to donate (Morgan & Cannon, 2003). To collect data, the presidents of the National Association for the Advancement of Colored People (NAACP) were asked to distribute the questionnaire to members in New Jersey, and New Jersey Sharing Network's AA Planning Committee, and other community partners were also asked to distribute the survey to AAs in New Jersey (Morgan & Cannon, 2003). The survey consisted of items that covered topics including knowledge about donation, attitudes towards donation, religious and subjective norms, bodily integrity, and medical mistrust (Morgan & Cannon, 2003).

Results revealed that about 40.0% of the participants carried a donor card, and of those who signed a donor card, 76.8% had discussed donation intentions with family

members (Morgan & Cannon, 2003). Further, only 44.7% of nondonors had discussed donation intentions with family members (Morgan & Cannon, 2003). Additionally, family discussions were found to be one of the most influential and important sources of information about donation, with 42.0% of participants receiving donation information from family members (Morgan & Cannon, 2003). Participants who expressed a willingness to donate organs were found more likely to obtain information about donation from family members, compared to participants without donor cards (Morgan & Cannon, 2003). This study suggests social norms are very powerful factors in decisions about donation, thus, encouraging family discussions about donation among AAs is crucial and a suggested strategy for increasing donor rates (Morgan & Cannon, 2003).

First-hand knowledge of someone who has experienced transplant, a norm of distrust in the healthcare system, and religious norms that support donation all appear to influence donation rates, among AAs. Studies have also begun to investigate the impact and role of family discussions about donation and the social norms around donation. But, in spite of this apparent importance of norms, however, there are still very limited studies that have directly investigated the influence of norms on donation decision making.

Aims of the Current Study

By performing a secondary data analysis of data collected from the baseline questionnaire distributed to participants prior to participation in the intervention activities of Giving ACTS (Giving ACTS: About Choices in Transplantation and Sharing), this study addresses the following aims and hypotheses:

Aim 1: Assess the association between social norms and organ donation intentions, among AAs.

a. H1: Those who believe a loved one is in favor of organ donation would demonstrate stronger intentions to become an organ donor.
b. H2: Those who believe a loved one would influence their decision about organ donation would demonstrate stronger intentions to become an organ donor.

Aim 2: Assess the association between social norms and expression of organ donation intentions via designation on one's driver's license, among AAs.

a. H3: Those who believe a loved one is in favor of organ donation would demonstrate an increased likelihood of expression of organ donation intentions via designation on their driver's license.
b. H4: Those who believe a loved one would influence their decision about organ donation would demonstrate an increased likelihood of expression of organ donation intentions via designation on their driver's license.

Aim 3: Assess whether a loved one's level of influence over decisions about organ donation moderates the relationship between a loved one's level of favorability towards organ donation and one's organ donation decision making, among AAs.

a. H5: The relationship between a loved one's level of favorability towards organ donation and actual donation intentions is moderated by a loved one's level of influence over organ donation decisions.

b. H6: The relationship between a loved one's level of favorability towards organ donation and expression of donation intentions via designation on a driver's license is moderated by a loved one's level of influence over organ donation decisions.

Investigating how social norms influence any health behavior is crucial. Social norms can substantially impact the knowledge and attitudes people have towards health behaviors. This means investigating social norms is vital for public health practice and the development of interventions. Social norms can inhibit behavior change or help positively influence behavior change; thus they warrant much attention. Further, social norms in different racial/ethnic, social, or age groups are of importance, as well. The diversity of the norms and their level of influence over the particular group or population are significant characteristics that should be well investigated and defined for the purposes of future research and interventions.

Currently, there is limited research and knowledge on the role of social norms on donation decision making, among AAs. Findings from this study have important implications for the problem of disproportionately low numbers of AAs who are registered donors. Understanding how social norms may inhibit or encourage AAs to becoming donors can help inform further research.

Further, accomplishing study aims will help inform future research and interventions on deceased donation, among AAs. This study aimed to not only contribute research to the current gap in the understanding of how social norms relate to the attitudes, knowledge, and behaviors around donation, but also to stimulate more work in this area,

particularly related to educational campaigns and interventions to increase public commitment to donation. Organ donation and transplantation provide life saving medical treatment options, presenting many individuals with the opportunity for a second chance at life. With the demand for organs increasing, research and interventions in this area are crucial. Thus, this study intended to stress and highlight the importance of donation, the need for organ donors, and the demand for research and interventions aimed at increasing the number of organ donors.

Chapter Three: Methodology

Study Design

This cross-sectional study is part of a larger parent study, Giving ACTS, a population based intervention aimed at evaluating the effectiveness of a culturally sensitive organ and tissue donation intervention for AA adults. The goal of the parent study is to determine whether the intervention activities were related to an increase in donation knowledge and improved attitudes and beliefs towards organ and tissue donation among AAs, as well as increased registration on the donor registry among AAs living in the area of the study. To achieve this goal, research was conducted in areas with the lowest rates for donation registration, which would allow the intervention to have the greatest effect and allow for the greatest increase in the number of registrants.

This study was conducted in Atlanta, Georgia, within the five counties that originally comprised the Atlanta metropolitan area (Clayton, Cobb, Fulton, DeKalb, and Gwinnett counties). Using 2010 Census track data and data from the Georgia state donor registry, 16 matched pairs of zip codes were identified within the metropolitan Atlanta area. These zip codes had high percentages of AA residents and low percentages of registered donors within the population. Within each matched pairs, the zip codes were randomized to either the intervention condition or the control condition. In the zip codes assigned to the intervention condition there were educational sessions held to encourage registration on the state donor registry; in the zip codes assigned to the control condition no such sessions were convened.

Sample and Procedure

To recruit participants for the study, 10 CWs were hired and trained. The CWs were selected based on meeting designated criteria, which was their demographic similarity to the target population, residency in or near one of the selected study zip codes, and their ability to assemble a variety of people. The CWs were tasked with recruiting participants residing in their assigned zip code and delivering the educational session in a group setting, to raise awareness about the importance of donation.

The sample of 425 participants included in this study came directly from the larger parent study, and met the eligibility criteria established for participation in the study. Individuals were considered eligible for participation if they were at least 18 years old, resided in the zip code in which the study was occurring, and self-identified as Black or AA. As defined in participation requirements outlined in the parent study, the term "Black" refers to people of African descent, regardless of cultural identification. Failure to meet these eligibility criteria or not understanding English eliminated individuals from participation in the study.

Measures

This study was designed to be a secondary data analysis of data collected from the baseline questionnaire of the parent study. The baseline instrument of 65 items included measures of attitudes about donation and transplantation, knowledge and understanding of the donation system, norms, personal experiences with donation and transplantation, donation decision making, attitudes toward financial incentives for donation, attitudes toward an opt-out donation system, and demographic questions. For this study, the two

primary variables of interest were social norms and organ donation decision making. Further, five potential confounding demographic variables were of interest, which were gender, age, educational level, employment status, and marital status. Scales of each study variable and demographic variables of interest are described below.

Social norms. Social norms were assessed using a two-item scale. The first item examined the participants' perceptions about a loved one's level of favorability of donation. Specifically, this item asked participants, "Think about the most important person in your life. Do you believe this person is in favor of organ donation?" Answer options for this item ranged from (1) definitely not to (7) definitely yes.

The second item assessed participants' perceptions of a loved one's level of influence over their own decision about donation. This item asked participants, "Think about the most important person in your life. How likely is it that this person will influence your decision about organ donation?" The answer options ranged from (1) very unlikely to (7) very likely.

Organ donation decision making. The outcome, organ donation decision making, was assessed using two items. The first item assessed the participants' intentions to become a donor, by asking participants to check, Yes, No, or Unsure to the following statement, "I intend to be an organ donor."

The second item evaluated whether participants have expressed donation intentions. This item asked participants, "I have expressed my donation intentions by the following: (check all that apply)," with answer options including, "Signing a donor card

or registering online," "Designating myself on my driver's license," "Sharing my wishes with a loved one/family member," and "None of the above." For the purposes of this study, investigators only focused on the answer option, "Designating myself on my driver's license," and whether participants checked this answer option on the questionnaire.

Demographics. Five demographic variables were also assessed as potential confounding variables. These variables were various demographic items asked on the questionnaire, which were gender, age, education level, employment status, and marital status.

Data Analysis

The data analysis portion of this study was conducted in accordance to the study aims and hypotheses of each study aim. The statistical software SPSS was used for all the statistical calculations and a p-value of less than 0.05 was used as the level of statistical significance.

To begin, frequencies and descriptives on all study variables and demographic variables of interest were assessed. After examining the distribution of each variable, it was found that the social norms variables were not normally distributed. To address this, a median split was performed on both of the social norms variables. To perform the median split, the median of each social norms variable was determined, and then the medians of each variable were used as the point to dichotomize the variables and create two categories for each variable.

The first predictor, a loved one's level of favorability of donation, was divided into two groups, using the variable's median of 5.14. These groups represented a "low" level of favorability of donation and a "high" level of favorability of donation. The second predictor, a loved one's level of influence over one's decision about donation, was divided into two groups, using the variable's median of 4.63. These groups represented a "low" level of influence over one's decision about donation and a "high" level of influence over one's decision about donation. Ultimately, both social norms variables were used as dichotomous variables in the remainder of the analyses.

Additionally, one outcome variable of interest, donation intentions, was recoded from a three-level categorical variable to a dichotomous variable with two response options, No/Unsure and Yes. This recode was performed to make the answer categories more equally distributed.

Further, the distribution of the demographic variable age was also not normally distributed. To address this, the age variable was transformed using a Logarithmic 10 transformation method, because the distribution of the variable was substantially positively skewed (Tabachnick & Fidell, 2007). The transformed age variable was then used in the remainder of the analyses.

Next, the relationships between demographic variables and study variables were analyzed, using T-tests and Chi-Square Tests. Four T-tests were conducted to analyze the relationships between age and each of the study variables. Additionally, 16 Chi-Square Tests were performed to analyze the remaining demographic variables, which were gender, education level, employment status, and marital status, and each of the study variables of interest.

Bivariate level analyses were then conducted between each predictor and outcome of interest. Specifically, four Chi-Square tests were performed to assess the relationships between each social norms variable and each organ donation decision making variable.

The final set of analyses tested each aim of this study and the hypotheses for each aim. Each of these analyses controlled for age in the model because this variable demonstrated significance at the bivariate level. These analyses are broken down by study and hypotheses of each study aim and were performed as follows:

Aim 1: Assess the association between social norms and organ donation intentions, among AAs.

Two logistic regressions were performed to test the hypotheses pertaining to aim 1.

a. H1: Those who believe a loved one is in favor of organ donation would demonstrate stronger intentions to become an organ donor.

A logistic regression was performed to assess the association between a loved one's level of favorability of donation and one's intentions to become a donor, while controlling for age.

b. H2: Those who believe a loved one would influence their decision about organ donation would demonstrate stronger intentions to become an organ donor.

A logistic regression was performed to assess the association between a loved one's level of influence over one's decision about donation and one's intentions to become a donor, while controlling for age.

Aim 2: Assess the association between social norms and expression of organ donation intentions via designation on one's driver's license, among AAs.

Two logistic regressions were performed to test the hypotheses pertaining to aim 2.

a. H3: Those who believe a loved one is in favor of organ donation would demonstrate an increased likelihood of expression of organ donation intentions via designation on their driver's license.

A logistic regression was performed to assess the association between a loved one's level of favorability of donation and one's expression of donation intentions via designation on one's driver's license, while controlling for age.

b. H4: Those who believe a loved one would influence their decision about organ donation would demonstrate an increased likelihood of expression of organ donation intentions via designation on their driver's license.

A logistic regression was performed to assess the association between a loved one's level of influence over one's decision about donation and one's expression of donation intentions via designation on one's driver's license, while controlling for age.

Aim 3: Assess whether a loved one's level of influence over decisions about organ donation moderates the relationship between a loved one's level of favorability towards organ donation and one's organ donation decision making, among AAs.

Moderation was tested using procedures outlined by Baron and Kenny (1986). In each of the following models, moderation would be evidenced by a significant interaction term while controlling for the main effects of the two social norms predictor variables.

a. H5: The relationship between a loved one's level of favorability towards organ donation and actual donation intentions is moderated by a loved one's level of influence over organ donation decisions.

A logistic regression was performed to assess whether the social norms interaction term was significantly associated with donation intentions, while controlling for the main effects of the social norms variables and age.

b. H6: The relationship between a loved one's level of favorability towards organ donation and expression of donation intentions via designation on a driver's license is moderated by a loved one's level of influence over organ donation decisions.

A logistic regression was performed to assess whether the social norms interaction term was significantly associated with expression of donation intentions via designation on one's driver's license, while controlling for the main effects of the social norms variables and age.

Chapter Four: Results

A sample of 425 participants from the larger parent study, Giving ACTS, was included in the current study.

Demographic Characteristics

A summary of demographic characteristics and study variables of interest of the participant sample are provided in Table 1. The average age of participants was 49 years old (SD=17.73), and over half of participants (n=274, 64.8%), identified as female.

The two social norms variables of interest were both dichotomized using the median value of each variable. As a result, a loved one's level of favorability of donation was divided into "high" and "low" groups, using the median of 5.14. Over half of participants (n=211, 51.2%), reported a loved one having a high level of favorability of donation. Additionally, a loved one's level influence over one's decision about donation was divided into "high" and "low" groups, using the median of 4.63. For this item, over half of participants (n=238, 58.2%), reported a loved one having a high level of influence over their decision about donation. Refer to the Appendix for Table 1.

Demographic Variables with Study Variables

After analyzing the relationships between all demographic variables and study variables, the only demographic variable that demonstrated significance was age, in relation to both donation intentions ($t[395]=2.21$; $p=0.03$), and expression of donation intentions via designation on one's driver's license ($t[399]=2.56$; $p\leq 0.01$).

Bivariate Analyses: Social Norms and Organ Donation Decision Making

Results of the bivariate analyses indicated that a loved one's level of favorability of donation is significantly associated with donation intentions ($p \leq 0.01$), and expression of donation intentions via designation on one's driver's license ($p=0.004$). Further, results suggest that a loved one's level of influence over one's decision about donation is significantly associated to donation intentions ($p=0.03$), but not significantly associated with expression of donation intentions via designation on one's driver's license ($p=0.55$).

Multivariate Analysis by Study Aim

The multivariate analyses tested each study aim and the hypotheses for each aim.

Aim 1. Assess the association between social norms and organ donation intentions, among AAs.

Two logistic regressions were performed to test the hypotheses pertaining to study aim 1, and results are displayed in Table 2. Hypothesis 1 was that those who believe a loved one is in favor of organ donation would demonstrate stronger intentions to become an organ donor. Results suggest that a loved one's level of favorability of donation is significantly associated to intentions to become a donor, when controlling for age. Specifically, those who believe that a loved one has a high level of favorability of donation are 2.14 times more likely to have intentions to become a donor, compared to those who believe a loved one has a low level of favorability of donation, when controlling for age (OR=2.14; $p \leq 0.01$).

Hypothesis 2 was that those who believe a loved one would influence their decision about organ donation would demonstrate stronger intentions to become an organ donor. Results suggest that a loved one's level of influence over one's decision about donation is not significantly associated with intentions to become a donor, when controlling for age (OR=1.47; p=0.07). Refer to the Appendix for Table 2.

Aim 2. Assess the association between social norms and expression of organ donation intentions via designation on one's driver's license, among AAs.

Two logistic regressions were performed to test the hypotheses pertaining to study aim 2, and results are displayed in Table 2. Hypothesis 3 was that those who believe a loved one is in favor of organ donation would demonstrate an increased likelihood of expression of organ donation intentions via designation on their driver's license. Results suggest that a loved one's level of favorability of donation is significantly associated with expression of donation intentions via designation on one's driver's license, when controlling for age. Specifically, those who believe that a loved one has a high level of favorability of donation are 1.71 times more likely to express donation intentions via designation on their driver's license, compared to those who believe that a loved one has a low level of favorability of donation, when controlling for age (OR=1.71; $p\leq$0.01).

Hypothesis 4 was that those who believe a loved one would influence their decision about organ donation would demonstrate an increased likelihood of expression of organ donation intentions via designation on their driver's license. Results suggest that a loved one's level of influence over one's decision about organ donation is not significantly associated to expression of donation intentions via designation on one's

driver's license, when controlling for age (OR=1.07; p=0.77). Refer to the Appendix for Table 2.

Aim 3: Assess whether a loved one's level of influence over decisions about organ donation moderates the relationship between a loved one's level of favorability towards organ donation and one's organ donation decision making, among AAs.

Two logistic regressions were performed to test the hypotheses pertaining to study aim 3, and results are displayed in Table 3. Hypothesis 5 was that, the relationship between a loved one's level of favorability towards organ donation and actual donation intentions is moderated by a loved one's level of influence over organ donation decisions. Influence, favorability, as well as the interaction term of level of influence and level of favorability combined, and age, were included in the model. Results indicate that a loved one's level of influence over decisions about donation does not moderate the relationship between a loved one's level of favorability towards donation and donation intentions, when controlling for age, because the interaction term was not significant in the model (OR=0.67; p=0.37).

Hypothesis 6 was that the relationship between a loved one's level of favorability towards organ donation and expression of donation intentions via designation on a driver's license is moderated by a loved one's level of influence over organ donation decisions. An identical model to the previous moderation model was tested, which included all of the same variables, but the outcome of interest for this test was expression of donation intentions via designation on one's driver's license. Results indicate that a loved one's level of influence does not moderate the relationship between a loved one's

level of favorability of donation and expression of donation intentions via designation on one's driver's license, when controlling for age, because the interaction term was not significant in the model (OR=0.77; p=0.55). Refer to the Appendix for Table 3.

Chapter Five: Discussion

Introduction and Summary of Findings

The purpose of the current study was to determine whether social norms impact donation decision making, among AAs. Using survey responses from participants in the larger parent study, Giving ACTS, associations between social norms and donation decision making were tested using logistic regression analyses. Overall, participants reported that social norms influence their donation decision making. Specifically, participants reported that a loved one's level of favorability of donation impacts their donation intentions and expression of donation intentions via designation on their driver's license. These findings support the claims established by TRA, which is that normative beliefs, or whether important individuals in a person's life approve or disprove of a particular behavior, directly influences one's intentions to perform that behavior and the action of performing that behavior (Montaño & Kasprzyk, 2008). Further these results agree with findings of previous studies, which have demonstrated significant associations between social norms and donation intentions and expression of donation intentions, among AAs (Morgan, 2006; Park et al., 2009; Weber et al., 2007). Findings related to each research question are discussed below.

1. What is the association between social norms and organ donation intentions, among AAs?

The first aim of this study was to assess the association between social norms and organ donation intentions, among AAs. This aim was driven by two hypotheses. The first

hypothesis was, those who believe a loved one is in favor of organ donation would demonstrate stronger intentions to become an organ donor. The second hypothesis was, those who believe a loved one would influence their decision about organ donation would demonstrate stronger intentions to become an organ donor.

Results testing this aim indicated a significant association between a loved one's level of favorability of donation and donation intentions. Specifically, participants who believed a loved one had a high level of favorability of donation were more likely to have intentions to become a donor. Further, the association between a loved one's level of influence over donation decision making and donation intentions, approached significance, but was not significant at the $p<0.05$ level. Thus, whether participants believed a loved one had a high or low level of influence over their donation decision making did not impact their donation intentions.

Findings from the current study relate to the literature. Results from Park et al. (2009) demonstrated that social norms impact intentions to enroll in the state donor registry and intentions to talk with family about donation. Further, findings from Weber et al. (2007) indicated that social norms influence intentions to sign a donor card. The current study differs from these studies which measured social norms only by a loved one's, a family member's, or a friend's level of favorability of donation, while the current study included a loved one's level of favorability of donation in the measure of social norms (Park et al., 2009; Weber et al., 2007). A study done by Morgan (2006) measured level of favorability and level of influence to evaluate social norms, and demonstrated that social norms predicted willingness to donate organs, among AAs. While results from the current study only found a significant association between level of favorability of

donation and donation decision making, these findings provide an opportunity for future research to continue to investigate the roles level of favorability and level of influence play in donation decision making, among AAs.

2. What is the association between social norms and expression of organ donation intentions via designation on one's driver's license, among AAs?

The second aim of this study was to assess the association between social norms and expression of organ donation intentions via designation on one's driver's license, among AAs. This aim was driven by two hypotheses. The first hypothesis was, those who believe a loved one is in favor of organ donation would demonstrate an increased likelihood of expression of organ donation intentions via designation on their driver's license. The second hypothesis was, those who believe a loved one would influence their decision about organ donation would demonstrate an increased likelihood of expression of organ donation intentions via designation on their driver's license.

Results demonstrated a significant association between a loved one's level of favorability of donation and expression of donation intentions via designation on one's driver's license. Specifically, participants who believed a loved one had a high level of favorability of donation were more likely to express donation intentions on their driver's license. Further, results indicated that there was not a significant association between a loved one's level of influence over donation decision making and expression of donation intentions via designation on one's driver's license. Thus, whether participants believed a loved one had a high or low level of influence over their donation decision making did not impact whether they expressed donation intentions on their driver's license.

While previous literature has not explored the relationship between social norms and expression of donation intentions via designation on a driver's license, these results provide a platform for future research and justify the need for more investigations in this area. The absence of research on this topic may be due to the fact that very few studies have investigated the impact of social norms on donation decisions, particularly written donation intentions.

Additionally, the relationship between a loved one's level of influence over donation decisions and expression of donation intentions via designation on one's driver's license was not significant at the bivariate level. This may also contribute to why there was not a significant association found in this model.

3. Does a loved one's level of influence over decisions about organ donation moderate the relationship between a loved one's level of favorability towards organ donation and one's organ donation decision making, among AAs?

The third aim of this study was to assess whether a loved one's level of influence over decisions about organ donation moderates the relationship between a loved one's level of favorability towards organ donation and one's organ donation decision making, among AAs. This aim was driven by two hypotheses. The first hypothesis was, the relationship between a loved one's level of favorability towards organ donation and actual donation intentions is moderated by a loved one's level of influence over organ donation decisions. The second hypothesis was, the relationship between a loved one's level of favorability towards organ donation and expression of donation intentions via

designation on a driver's license is moderated by a loved one's level of influence over organ donation decisions.

The results demonstrated a lack of evidence for moderation in both models. In other words, a loved one's level of influence over donation decisions does not moderate the relationship between a loved one's level of favorability of donation and donation decision making. Results may relate to other findings from the current study, which indicate that a loved one's level of influence did not impact participants' donation intentions nor expression of donation intentions via designation on their driver's license.

The absence of family discussions about donation among AAs may relate to why a loved one's level of influence was not significantly associated to donation decision making in the current study. Related to social norms, previous literature has illustrated that family discussions play a major role in donation decision making (Brown, 2012; McNamara et al., 1999; Morgan et al., 2003; Morgan & Cannon, 2003). Studies have indicated that family discussions about donation are an important source for donation information, among AAs (Morgan & Cannon, 2003). But, while these family discussions about donation have been found influential on donation intentions, studies have indicated that these discussions rarely occur (Brown, 2012; McNamara et al., 1999; Minniefield et al., 2001). Yet among AAs who expressed a willingness to donate, they were more likely to obtain information about donation from family members, which support the need for more family discussions (Morgan & Cannon, 2003). Family discussions are an important information channel for disseminating knowledge, attitudes, and beliefs about donation, and can have major implications on one's perceptions about loved one's level of favorability of donation and level of influence over donation decisions. Without these

discussions about donation, a loved one's level of influence could be greatly reduced. The current study did not look at whether these discussions were taking place among the participants and their loved ones, but future research should consider looking into these discussions, whether they are occurring, and what topics are being discussed.

Another possibility for why participants' beliefs about a loved one's level of influence did not impact participants' donation decision making could be due to the demographics of the participants. The majority of participants were single, in their upper 40's, and female, which may have many implications for why level of influence did not impact participants' donation decision making.

Finally, the point at which the level of influence variable was dichotomized may have also contributed to why this variable was not significant in any of the models. While the current study used the median as the point to transform the continuous variable into a dichotomous variable, there are other methods that could have been used to address the non-normal distribution of the variable. The point at which the variable was split may have impacted the results of the current study. Thus, future research should attempt to utilize continuous variables to achieve more power and robustness.

Strengths and Limitations

The current study included several noteworthy strengths. First, this study was unique in that it measured expression of donation intentions via designation on one's driver's license. No other studies found in the literature looked at written expression of donation intentions on a driver's license in relation to social norms, thus this study is the first in its kind. Another strength of this study is that it was informed by theory. The TRA

helped guide the understanding behind how social norms are impact donation intentions and expression of donation intentions.

This study also benefited from a large sample size. With a larger sample size, there is less concern about the statistical significance of the findings, because as the sample size increases, statistical significance is more likely to be achieved (Crosby, Salazar, & DiClemente, 2006). The current study had a sample size of 425 participants, thus the study's power and ability to detect true associations were not of concern.

But, while this study had several strengths, this research was not without limitations, which must be acknowledged. One limitation of this study was the cross-sectional study design. While research using a cross-sectional study design can oftentimes be relatively less time consuming and reasonably inexpensive, this design has significant limitations (Salazar, Crosby, & DiClemente, 2006). Conclusions about some aspects of the associations yielded in the results, particularly in temporality, directionality, and causation, are limited due to the cross-sectional design of this study (Salazar, Crosby, & DiClemente, 2006). Cross-sectional studies are unable to determine cause and effect relationships, weakening the internal validity of the results (Salazar, Crosby, & DiClemente, 2006). Further, these types of studies cannot establish a temporal sequence of events between exposure and outcome (Salazar, Crosby, & DiClemente, 2006). In this study, organ donation decision making and social norms were evaluated at one point in time (i.e., when the baseline survey was administered). Thus, this research was only able to assess the levels of these items within the sample and cannot establish any temporal relationships between the variables.

Second, several types of bias may have impacted the results. Bias may have been introduced to this study by the transformation of the social norms variables. The social norms variables were collected continuously and then dichotomized within the analyses process due to the non-normal distribution of these variables. While transforming continuous variables into dichotomous variables is one method for addressing the normality issue, the variables become less robust and some of the variance is lost. Thus, future research should utilize continuous variables in analyses, if possible.

Social desirability may have also biased the results. These analyses used data that were self-reported by participants, and because of this, participants may have answered the questions in ways that they believed the questions should be answered, by putting socially desirable answers, and did not answer in a way that would reflect their true thoughts and behaviors.

Another limitation of this study lies in the sampling procedure used to recruit participants. The study used a passive recruitment technique by employing CWs to acquire the sample of participants. Participants who were more willing to volunteer for the study may have been more supportive of donation or have a greater interest in donation, compared to those who chose not to participate, which has been a concern in previous studies (Arriola et al., 2010). This could result in selection bias and, therefore, further jeopardize the generalizability of results.

Further, the questionnaire used in this study did not include an item where participants could specify the loved one in their life they thought of when answering the social norms items. Gaining an understanding of the individual or individuals the

participants were thinking of when responding to these questions would have provided additional context to the results and may have helped explained some of the findings.

In addition, the current study did not look at verbal expression of donation intentions, such as talking with family members about donation wishes. The expression of donation intentions item on the questionnaire did include a response option that allowed participants to indicate whether they have expressed their donation intentions by sharing their wishes with a loved one/family member. This study did not include this form of expression of donation intentions, but future research should consider investigating this form of expression of donation intentions and the relationship between this form of expression and social norms.

Finally, participants in this study were overwhelmingly female. Other studies related to the larger parent study have also reported the participant samples to be predominately female (Arriola et al., 2010; Arriola et al., 2013). A female dominated sample may have impacted the results from the current study, and this should be a consideration in future research.

Implications

This research offers several implications for the field of public health. Investigating how social norms influence any health behavior is crucial. Social norms have substantial impact upon the knowledge and attitudes people have towards health behaviors. This means investigating social norms is vital for public health practice and construction of interventions. Social norms can inhibit behavior change or help positively influence behavior change; thus they warrant much attention. Further, social norms in

different racial/ethnic, social, or age groups are of importance, as well. The diversity of the norms and their level of influence over the particular group or population are significant characteristics that should be well investigated and defined for the purposes of future research and interventions.

Recommendations for Future Research

Findings from this study have many implications for future research. First, future research should consider performing more preliminary, exploratory analyses on the social norms involving and impacting donation decisions among AAs. A deeper understanding of the social norms around donation could be achieved through the use of qualitative methods, such as focus groups or interviews. While qualitative studies also have limitations, this type of research may be a good step in assessing the current perceived and understood social norms around donation, among AAs.

Another route for future research based on the findings of the current study is to look more closely at loved ones' beliefs and influence on donation. More specifically, studies could investigate the differences among loved ones on their level of favorability of donation and their level of influence over donation decisions. While this study only found that level of favorability was significantly associated with donation decision making, the loved ones who participants were thinking of when answering these questions is unknown. Thus, understanding how different family members, friends, and loved ones impact one's donation beliefs and intentions is of importance for future research.

Additionally, future research should consider looking further into the association of age and social norms and donation decision making, among AAs. Specifically, studies could investigate whether differences in social norms exist by age, among AAs. The current study indicated that age was significantly associated with donation intentions and donation expression. It would be of interest to look at the social norms of individuals at various ages, how they differ, and the impact these social norms have on donation decision making among individuals at different ages.

Further, future studies should explore how social norms impact both verbal and written donation intentions, among AAs. The current study was limited to written expression of donation intentions via designation on one's driver's license. But, previous research has demonstrated discussion with family members about donation wishes plays a significant role in disseminating information about donation and donation intentions, among AAs (Brown, 2012; McNamara et al., 1999; Morgan et al., 2003; Morgan & Cannon, 2003). Thus, future studies should consider how social norms influence family discussions around donation and sharing donation wishes with loved ones, family, and friends.

Overall, this study helps fill a gap in the current research on donation, among AAs. Research on how social norms play into donation decisions among AAs is limited, indicating a great need for work to be done in this area. This study aimed to not only contribute research to this current gap in the understanding of how social norms play into the intentions and behaviors around donation, but also to stimulate more work to be done in this area, particularly related to educational campaigns and interventions to increase donation.

Increasing the number of registered donors can have major implications for providing the life saving procedure of organ transplantation, which for many is a second chance at life. This study demonstrated that social norms influence whether individuals become donors. Thus, investigating how to increase the number of donors, particularly through understanding social norms about donation, can greatly contribute to this field and advance work done in this area.

References

Ajzen, I. (1991). The Theory of Planned Behavior. *Organizational Behavior and Human Decision Processes*, *50*, 179–211.

Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behavior*. Englewood Cliffs, CA: Prentice Hall.

Arriola, K. R., Perryman, J. P., & Doldren, M. (2005). Moving beyond attitudinal barriers: understanding African Americans' support for organ and tissue donation. *Journal of the National Medical Association*, *97*(3)*,* 339-350.

Arriola, K. R., Perryman, J. P., Doldren, M. A., Warren, C. M., & Robinson, D. H. (2007). Understanding the role of clergy in African American organ and tissue donation decision-making. *Ethnicity and Health, 12*(5), 465-482. doi: 10.1080/13557850701616896

Arriola, K. R., Robinson, D. H., Perryman, J. P., & Thompson, N. (2008). Understanding the relationship between knowledge and African Americans' donation decision-making. *Patient Education and Counseling, 70*(2), 242-250. doi: 10.1016/j.pec.2007.09.017

Arriola, K. R., Robinson, D. H., Perryman, J. P., Thompson, N. J., & Russell, E. F. (2013). Project ACTS II: organ donation education for African American adults. *Ethnicity & Disease, 23*(2), 230-237.

Arriola, K., Robinson, D. H., Thompson, N. J., & Perryman, J. P. (2010). Project ACTS: an intervention to increase organ and tissue donation intentions among African Americans. *Health Education & Behavior, 37*(2), 264-274. doi: 10.1177/1090198109341725

Baron, R. M., & Kenny, D.A. (1986). The Moderator-Mediator Variable Distinction in Social Psychological Research: Conceptual, Strategic, and Statistical Considerations. *Journal of Personality and Social Psychology, 51*(6), 1173-1182.

Brown, E. R. (2012). African American present perceptions of organ donation: a pilot study. *Association of Black Nursing Faculty Journal, 23*(2), 29-33.

Callender, C. O., Bayton, J. A., Yeager, C., & Clark, J. E. (1982). Attitudes among blacks toward donating kidneys for transplantation: a pilot project. *Journal of the National Medical Association, 74*(8)*,* 807-809.

Callender, C.O., Hall, M.B., & Branch, D. (2001). An assessment of the effectiveness of the Mottep model for increasing donation rates and preventing the need for transplantation--adult findings: program years 1998 and 1999. *Seminars in Nephrology. 21*(4). 419-428.

Crosby, R.A, Salazar, L.F., & DiClemente, R.J. (2006). Principles of Sampling. In R.A. Crosby, R.J. DiClemente, & L.F. Salazar, (Eds.), *Research Methods in Health Promotion* (pp. 289-316). San Francisco, CA: Jossey-Bass.

Donate Life America. (2014). *Multicultural Perspectives.* Retrieved from http://donatelife.net/understanding-donation/multicultural-perspectives/

Fishbein, M., & Ajzen, I. (1975). *Beliefs, attitude, intention, and behavior: An introduction to theory and research*. Reading, MA: Addison-Wesley.

Goldberg, D. S., Halpern, S. D., & Reese, P. P. (2013). Deceased organ donation consent rates among racial and ethnic minorities and older potential donors. *Critical Care Medicine, 41*(2), 496-505. doi: 10.1097/CCM.0b013e318271198c

Guadagnoli, E., McNamara, P., Evanisko, M. J., Beasley, C., Callender, C. O., & Poretsky, A. (1999). The influence of race on approaching families for organ donation and their decision to donate. *American Journal of Public Health, 89*(2), 244-247.

McNamara, P., Guadagnoli, E., Evanisko, M. J., Beasley, C., Santiago-Delpin, E. A., Callender, C. O., & Christiansen, E. (1999). Correlates of support for organ donation among three ethnic groups. *Clinical Transplantation, 13*(1 Pt 1), 45-50.

Minniefield, W. J., Yang, J., & Muti, P. (2001). Differences in attitudes toward organ donation among African Americans and whites in the United States. *Journal of the National Medical Association*, *93*(10), 372-379.

Montaño, D.E., & Kasprzyk, D. (2008). Theory of Reasoned Action, Theory of Planned Behavior, and the Integrated Behavioral Model. In K. Glanz, B. K. Rimer, & K. Viswanath, (Eds.), *Health Behavior and Health Education: Theory, Research, and Practice* (pp. 67-96). San Francisco, CA: Jossey-Bass.

Morgan, S. E. (2006). Many facets of reluctance: African Americans and the decision (not) to donate organs. *Journal of the National Medical Association, 98*(5), 695-703.

Morgan, S. E., & Cannon, T. (2003). African Americans' knowledge about organ donation: closing the gap with more effective persuasive message strategies. *Journal of the National Medical Association, 95*(11), 1066-1071.

Morgan, S.E., Miller, J.K., & Arasaratnam, L.A. (2003). Similarities and Differences Between African Americans' and European Americans' Attitudes, Knowledge,

and Willingness to Communicate About Organ Donation. *Journal of Applied Social Psychology, 33*(4), 693-715.

National Research Council. (1999a). Access to Transplantation. In F. Poillon & B. Gyorgy (Eds.), *Organ Procurement and Transplantation: Assessing Current Policies and the Potential Impacts of the DHHS Final Rule.* (pp. 39-48). Washington, D.C.: The National Academies Press.

National Research Council. (1999b). Organ Donation. In F. Poillon & B. Gyorgy (Eds.), *Organ Procurement and Transplantation: Assessing Current Policies and the Potential Impacts of the DHHS Final Rule.* (pp. 49-60). Washington, D.C.: The National Academies Press.

Organ Procurement and Transplantation Network. (2014a). *Overall by Organ: Current U.S. Waiting List.* Retrieved from http://optn.transplant.hrsa.gov/converge/latestData/rptData.asp

Organ Procurement and Transplantation Network. (2014b). *Overall by Organ: Current U.S. Waiting List, Georgia.* Retrieved from http://optn.transplant.hrsa.gov/converge/latestData/rptData.asp

Organ Procurement and Transplantation Network. (2015a). *Organ by Ethnicity: Current U.S. Waiting List.* Retrieved from http://optn.transplant.hrsa.gov/converge/latestData/rptData.asp

Organ Procurement and Transplantation Network. (2015b). *Overall by Organ: Current U.S. Waiting List.* Retrieved from http://optn.transplant.hrsa.gov/converge/latestData/rptData.asp

Park, H. S., Smith, S. W., & Yun, D. (2009). Ethnic differences in intention to enroll in a state organ donor registry and intention to talk with family about organ donation. *Health Communication, 24*(7), 647-659. doi: 10.1080/10410230903242259

Robinson, D. H., Klammer, S. M., Perryman, J. P., Thompson, N. J., & Arriola, K. R. (2014). Understanding African American's Religious Beliefs and Organ Donation Intentions. *Journal of Religion and Health*. doi: 10.1007/s10943-014-9841-3

Robinson, D. H., Perryman, J. P., Thompson, N. J., Amaral, S., & Arriola, K. R. (2012). Testing the utility of a modified organ donation model among African American adults. *Journal of Behavioral Medicine, 35*(3), 364-374. doi: 10.1007/s10865-011-9363-3

Russell, E., Robinson, D. H., Thompson, N. J., Perryman, J. P., & Arriola, K. R. (2012). Distrust in the healthcare system and organ donation intentions among African Americans. *Journal of Community Health, 37*(1), 40-47. doi: 10.1007/s10900-011-9413-3

Salazar, L.F., Crosby, R.A, & DiClemente, R.J. (2006). Choosing A Research Design. In R.A. Crosby, R.J. DiClemente, & L.F. Salazar, (Eds.), *Research Methods in Health Promotion* (pp. 75-106). San Francisco, CA: Jossey-Bass.

Siminoff, L. A., Burant, C. J., & Ibrahim, S. A. (2006). Racial disparities in preferences and perceptions regarding organ donation. *Journal of General Internal Medicine, 21*(9), 995-1000. doi: 10.1111/j.1525-1497.2006.00516.x

Tabachnick, B.G., & Fidell, L.S. (2007). Cleaning Up Your Act: Screening Data Prior to Analysis. In S. Hartman (Ed.), *Using Multivariate Statistics.* (pp. 60-116). Boston, MA: Pearson Education Inc.

United Network for Organ Sharing. (2013). *What Every Patient Needs to Know.* Retrieved from http://www.unos.org/docs/WEPNTK.pdf

United Network for Organ Sharing. (2014). *Transplant Trends.* Retrieved from http://www.unos.org/index.php

U.S. Census Bureau. (2014). *State & County Quick Facts.* Retrieved from http://quickfacts.census.gov/qfd/states/00000.html

U.S. Department of Health and Human Services. (2014a). *About Donation and Transplantation.* Retrieved from http://www.organdonor.gov/about/index.html

U.S. Department of Health and Human Services. (2014b). *African Americans and Organ Donation.* Retrieved from http://www.organdonor.gov/minortyaa/index.html

U.S. Department of Health and Human Services. (2014c). *FAQs Who Can Be A Donor.* Retrieved from http://www.organdonor.gov/faqs.html

U.S. Department of Health and Human Services. (2014d). *The Need is Real: Data.* Retrieved from http://www.organdonor.gov/about/data.html

U.S. Department of Health and Human Services. (2014e). *Why Donate?* Retrieved from http://www.organdonor.gov/whydonate/index.html

U.S. Department of Health and Human Services. (2014f). *Why Minority Donors Are Needed.* Retrieved from http://www.organdonor.gov/whydonate/minorities.html

U.S. Department of Health and Human Services. (2015a). *Organ and Tissue Donation from Living Donors*. Retrieved from http://www.organdonor.gov/about/livedonation.html

U.S. Department of Health and Human Services. (2015b). *Organ Donation*. Retrieved from http://organdonor.gov/about/organdonation.html

U.S. Department of Health and Human Services. (2015c). *Organ Donation: The Process*. Retrieved from http://www.organdonor.gov/about/organdonationprocess.html#process3

Weber, K., Martin, M. M., Corrigan, M., Members of COMM 160. (2007). Real Donors, Real Consent: Testing the Theory of Reasoned Action on Organ Donor Consent. *Journal of Applied Social Psychology, 37*(10), 2435-2450.

Yuen, C. C., Burton, W., Chiraseveenuprapund, P., Elmore, E., Wong, S., Ozuah, P., & Mulvihill, M. (1998). Attitudes and beliefs about organ donation among different racial groups. *Journal of the National Medical Association, 90*(1), 13-18.

Appendix

Table 1.

Demographic Characteristics of Study Participants, N=425

Variable	n (%)
Demographics	
Age, *m (SD)*	48.57 (17.73)
Gender	
Female	274 (64.8)
Male	149 (35.2)
Grade	
Less than high school	24 (5.8)
12th grade/GED	127 (30.8)
College	181 (43.9)
Professional degree	80 (19.4)
Employment	
Unemployed	84 (20.4)
Retired	117 (28.4)
Working part or full time	211 (51.2)
Marital Status	
Single	193 (47.3)
Married	99 (24.3)
Divorced, separated, widowed	116 (28.4)
Social norms	
Favorability towards donation	
Low	201 (48.8)
High	211 (51.2)
Influence on donation decision	
Low	171 (41.8)
High	238 (58.2)
Donation decision making	
Donation intentions	
No/unsure	195 (47.0)
Yes	220 (53.0)
Donation expression	
No	251 (59.1)
Yes	174 (40.9)

Note: Ns do not add up to 425 due to missing data

Table 2.

Donation Decision Making regressed on Social Norms

Study Variable	Odds Ratios	
	Outcome = Donation intentions	Outcome = Expression of donation intentions
Level of favorability	2.14**	1.71**
Level of influence	1.47+	1.07

**$p \leq 0.01$; *$p \leq 0.05$; +$p \leq 0.10$

Table 3.

Level of Favorability and Donation Decision Making Moderated by Level of Influence

Study Variable	Odds Ratios	
	Outcome = Donation intentions	Outcome = Expression of donation intentions
Level of favorability	2.67**	2.17*
Level of influence	1.38	0.97
Level of favorability * Level of influence	0.67	0.77

**$p \leq 0.01$; *$p \leq 0.05$; $^{+}p \leq 0.10$