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## Exploring Barriers to Organ Donation in the African-American Communities of California

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### Abstract

*There are a disproportionate number of African-Americans on transplant waiting lists across the country. The outcomes of a transplant are greatly improved when the donor and the recipient are from the same ethnic group. Sadly, the demand for cadaver organs in the African-American community exceeds the supply. Researchers in the past have sought to identify barriers to organ and tissue donation. To date, the studies have been conducted in the eastern and southern regions of the United States. This study examines whether the previously identified barriers are applicable in the African-American communities of California. A revised version of the Bone Marrow Donation Intention Tool was administered both in person and online. A *t*-test was used for analysis. The findings revealed statistically significant agreement/disagreement statements. These statements indicated that the barriers to organ donation from other areas of the United States were not representative of the respondents on the west coast.*

**Key Words:** African-Americans, barriers, organ donation

### Introduction

As a former kidney transplant coordinator, the first author became aware that a disproportionate number of African-Americans with end stage renal disease were on the transplant waiting list. The United States Department of Health and Human Services Office of Minority Health states that African-Americans make up the largest group of minorities in need of an organ transplant (Organ Procurement Transplant Network, 2010). Sadly, the demand for cadaver organs far exceeds the supply. It became apparent that further study was needed to determine what the barriers were to organ donation in the African-American community. An exhaustive literature search, using the keywords "organ donation," "African-American," and "transplantation," yielded approximately six pertinent, recent, and scholarly journal articles.

### Background and Significance

Arriola, Robinson, Thompson, and Perryman (2010) conducted a study that evaluated the effectiveness of "Project ACTS (About Choices in Transplantation and Sharing)." Project ACTS is an intervention to increase organ and tissue donation intentions in African-Americans. The sample

included church-going African-American adults ( $N = 425$ ) within the southeastern region of the United States. Seventy-nine percent of the participants were female and the mean age of the sample was 49.5 years. The results of this randomized, longitudinal, effectiveness trial revealed that there were no significant differences between the control and the intervention groups regarding their donation intentions.

### Positive and Negative Factors Toward Organ Donation

Glasgow and Bello (2006) sought to identify and explore the factors that affected the intentions of African-Americans related to bone marrow donation. The participants were African-American adults ( $N = 224$ ) in Philadelphia, PA, from a variety of socioeconomic backgrounds. Sixty-nine percent of the participants were female ( $n = 153$ ) and 31% were male ( $n = 67$ ). The mean age range was 32.9 years ( $SD = 12.7$ ). The researchers chose an exploratory, descriptive design for the study, which included the Bone Marrow Donation Intention Tool, a 65-item Likert-type scale questionnaire. The tool, which was developed during the second phase, uncovered three major factors that served as barriers to the intention not to donate: (a) fear; (b) external influences; and, (c) concern about resources. The researchers also identified three factors that positively impacted the number of African-American bone marrow donors: (a) altruism; (b) external influences; and, (c) approval of others.

Morgan (2006) investigated the impact of three variables: (a) knowledge; (b) attitudes; and, (c) social norms. The researchers also identified three barriers: (a) medical mistrust; (b) bodily integrity; and, (c) religiosity. Three hundred African-Americans in the state of New Jersey completed a 13-item questionnaire adapted from several different scales. Their findings indicated that the support and involvement of African-American churches, plus improved knowledge, enhanced African-Americans' attitudes toward donation. The findings also suggested that any interventions aimed at increasing African-Americans' decision to donate must target knowledge and attitudes.

### The Importance of Family Discussion

Dodd-McCue and Tartaglia (2007) examined whether there were significant differences between African-American families who consented to organ and tissue donation and those who did not. The random sample included 120 African-

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American potential donor cases, collected over a period of seven years, at an academic medical center. Next-of-kin (NOK) relationships, family interactions, knowledge of donor wishes, family initiation of the donation discussion, and satisfaction with the donation process were the major variables of interest. The results of that study demonstrated that programs encouraging organ donation-related discussion among African-American families were important.

### Perceived Inequalities in Organ Donation

A qualitative study in Atlanta, GA, examined the role of clergy in African-Americans' decision to donate. Twenty-six African-American clergy participated in four focus groups with the goal of understanding the clergy's attitudes, beliefs, and experiences related to organ and tissue donation. The researchers determined that while the clergy was supportive of organ donation, there was concern regarding the perception that inequalities existed in the donation and transplantation system (Arriola, Perryman, Doldren, Warren, & Robinson, 2007).

Cort and Cort (2008) surveyed 182 African-American Seventh Day Adventist (SDA) college students from the South and 152 non-African-American SDA college students from the central U.S. Forty-one percent of the participants were male with a mean age of 21.8 years. Significantly more of the African-American SDA students believed that perceived racism in healthcare negatively impacted their willingness to donate ( $p < .01$ ). The African-American students were almost 70% less likely to consent to organ donation. Other barriers included: (a) thoughts of death; (b) concerns about body image; and, (c) a belief that physicians would withhold lifesaving measures if the patient were a designated organ donor.

Hall and colleagues (2007) studied the behavioral psychosocial measures that played a part in the intention to donate among African-Americans. The participants of this qualitative study were 344 African-American college students over the age of 17 that lived in the state of North Carolina. The researchers examined the stages of change, decisional balance, and self-efficacy as major issues that needed to be addressed in future interventions in order to increase the intention to donate. The findings showed that successful organ donation campaigns included the use of web-based interventions aimed at college populations. The inclusion of family members in the discussion and the intervention process played an important part in the willingness to increase donation rates.

The common theme among these articles was the acknowledgement of barriers to organ and tissue donation in the African-American community. The development and implementation of interventions that are designed to increase the willingness and the intentions of African-Americans to donate was also a common thread. Additionally, many of the articles emphasized the high need for organs and the low rates of donation. However, no researchers have examined the barriers to organ donation in African-Americans who reside on the west coast of the United States.

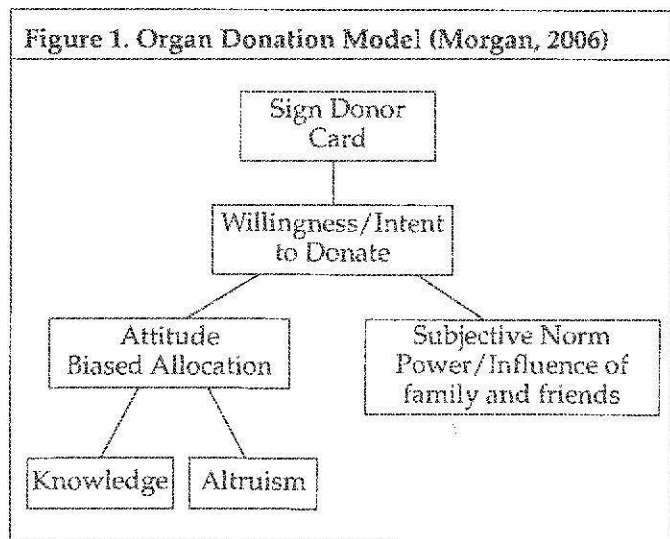
### Purpose of the Study

For many Americans who suffer from chronic, acute, or congenital organ failure, transplantation is the therapy of choice. Transplantation can not only extend one's life but also improve one's quality of life (Morgan, 2006). The current allocation process for organ transplantation in the United States involves placement on a waiting list until a compatible organ becomes available. Genetically compatible matches within one's own ethnic group usually have greater success. Chronic conditions such as diabetes, hypertension, and renal disease plague a disproportionate number of African-Americans. These conditions can lead to organ failure and, as a result, require transplantation (Glasgow & Bello, 2006). Although African-Americans comprise 12.6% of the U.S. population, they represent 34% of people waiting for a kidney transplant. In 2010, only 17% of all deceased donors were African-Americans (Organ Procurement Transplant Network). The identification of barriers is essential in order to develop effective interventions that lead to an increase in intention to donate. Therefore, the purpose of this study was to identify the barriers to organ donation in the African-American communities of northern and southern California.

**Research Question:** This quantitative study intended to survey the hypothesis that medical mistrust, lack of knowledge, and religious concerns negatively impacted the intention of California's African-Americans to become organ donors and answer the question: "What are the barriers to organ donation in the African-American communities of northern and southern California?"

### Conceptual Framework

The conceptual framework of the Organ Donation Model (Morgan, 2006) was the guide for this study. The Organ Donation Model combines the Theory of Reasoned Action (TRA) (Ajzen, 1991) with the variables of knowledge and attitudes. TRA suggests that a person's behavioral intention depends on the person's attitude about the behavior and subjective norms (Ajzen) (see Figure 1).



**Methodology**

**Study Design**

A non-experimental, descriptive, cross-sectional design was utilized. The researchers hypothesized that there would be a relationship between the variables of religious concerns, medical mistrust, knowledge, subjective norms, attitudes, and the intention to donate organs in the African-American community. For the purposes of this study "knowledge" was defined as overall knowledge related to the organ donation process. "Religious concerns" was defined as the questioning of whether there was a Biblical mandate related to organ donation. "Medical mistrust" referred to the unbiased allocation of organs to ethnic minorities. "Subjective norms" addressed the impact of the opinions that family and friends had on the person's decision to donate. "Attitude" measured the opinions related to organ donation (Morgan, 2006).

**Sample and Setting**

This study used a convenience sample of 144 ( $N = 144$ ) African-American adults. The inclusion criteria were that they were over 18 years of age and that they lived in Cali-

fornia. Participants were recruited via social media (Facebook), email, and two churches. The research was conducted at two predominantly African-American churches, one in northern California, and one in southern California. Each congregation averaged 100-200 members who were in attendance on any given Sunday.

**Instrumentation**

*The Bone Marrow Donation Intention Scale* (Glasgow & Bello, 2007) was used to measure organ donation intention. The Bone Marrow Donation Intention tool's author (Glasgow & Bello, 2007) granted permission to modify the scale to measure organ donation intention in African-Americans. The 33-question Likert scale has been validated for the study population of African-American adults. Many of the questions in the survey were equivalent, in the sense that they were either identical or were logically reversed. The elimination of those redundant questions, after the responses were collected, had the effect of reducing the number of independent questions to 22. Each question consisted of a statement and the respondents were asked to state their agreement or disagreement according to a

**Table 1. Survey Questions**

Question	Statement
5a	I know about the organ donation process.
5d	I would like to know more about the organ donation process.
6a	My church would approve of me donating my organs.
6c	My family would approve of me donating my organs.
6e	My friends would approve of me donating my organs.
7a	My fellow church members' opinions about whether I should donate my organs is important to me.
7b	When I think of organ donation, I think of saving someone's life.
7c	When I think of organ donation, I think of helping another person.
7d	I would give my organs to a stranger.
7e	I would give my organs to whoever needs them.
8a	I would only give my organs to children.
8b	The race of the person who gets my organs matters to me.
9a	African-Americans do not believe in giving their organs.
9b	African-Americans are more private about what is happening to their bodies.
9c	I seldom hear about African-Americans getting an organ transplant.
9d	Education about organ donation will not help African-Americans donate organs.
10a	African-Americans need to know about the organ donation process.
10c	I am convinced that important people get organs first.
10d	I am concerned that a White person would get my organs before an African-American.
10e	An African-American is less likely to get donated organs if they need them.
11a	Most people will take organs from anyone.
11b	The age of the person getting my organs is important in my decision to donate or not donate my organs.



Likert scale (1 = strongly disagree to 5 = strongly agree). The tool is both valid and reliable. The Cronbach's alpha coefficient for reliability is usually 0.70 with the exception of exploratory research, which allows for values below 0.70. The Cronbach's alpha was 0.83 for attitude, 0.80 for subjective norms, and 0.63 for intention (Glasgow, 2007) (see Table 1).

### Institutional Review Board Approval

Human Subjects approval was obtained from the participating churches and the affiliated university. Pastors from both congregations granted written permission to the primary researcher. Participants who completed the paper surveys were informed in a written statement that no identifying information would be collected. Online participants gave their implied consent by completing the survey.

### Data Collection

Self-report survey data was conducted online via e-mail and Survey Monkey® over a two-week time period. Paper copies of the survey were distributed at the conclusion of church services. The northern California parishioners were solicited to participate in the church parking lot by the primary investigator and assistants who collected the completed surveys. The southern California congregants were informed during the announcement portion of the service that surveys would be distributed and collected immediately following the morning service.

The primary investigator sent an email to Facebook and to personal and professional contacts inviting them to participate in a brief survey regarding organ donation. The email and Facebook message included a link to the online data collection website, Survey Monkey®. Respondents were able to click on the link, which took them directly to the survey. Additionally, some email participants forwarded the survey link to personal and professional contacts, who also met the survey criteria.

Of the 144 surveys collected, 94 of the respondents were from the online survey collector, Survey Monkey®, in addition to 27 northern California respondents and 23 southern California respondents who completed the paper versions.

### Data Analysis

The ultimate goal of the study was to determine what the barriers were to organ donation in order to develop effective interventions and increase the number of donors in the African-American community. The hypothesis examined the relationship between the variables and the willingness to donate; therefore, the level of measurement was ordinal with discrete variables. An analysis of Likert scores by question (Table 2) was performed using *t*-tests done in Excel ( $p < 0.05$ ). The questions in which the mean was statistically significantly greater than 3.0 (3 = neutral or "in the middle") are indicated by an asterisk (\*). Those questions in which the mean was statistically less than 3.0 (statistically significant disagreement with statement) are indicated by a cross (+). The remaining

questions are not considered to be statistically different from 3.0. (see Table 2).

### Findings

For questions 5a: "I know about the organ donation process," and 11a: "Most people will take organs from anyone," older respondents tended to be more in agreement with those statements than were younger respondents. For the remaining questions, it was concluded that age had no effect on the responses to those questions. None of the gender differences was considered to be statistically significant. Consequently, it can be concluded that gender had no effect on the responses to those questions. In only question 10e: "An African-American is less likely to get donated organs if they need them," were the native differences found to be statistically significant. The term "native" applies to participants who were born in the state of California, versus those who emigrated from other states ("non-natives"). For the remaining questions, it was concluded that nativity had no effect on the responses to those questions. None of the educational differences were considered to be statistically significant. Therefore, it was concluded that education had no effect on the responses to those questions.

The questions in Table 2 that show statistically significant agreement, are indicated by an asterisk (\*), while those questions that show statistically significant disagreement, are indicated by a cross (+) symbol. There was statistically significant agreement among respondents that they knew or would like to know more about organ donation. There was also statistically significant agreement that church, family, and friends would approve of the respondents' donation of organs. Study participants demonstrated agreement that the subject of organ donation is equated with saving someone's life and helping another person. Statistically, there was significant agreement with the willingness to give organs to whoever needs them. The questions related to willingness to donate and saving someone's life were designed to measure the degree of altruism associated with organ donation intention. Conversely, there was significant disagreement with the statements, "I would only give my organs to children," and, "The race of the person who gets my organs matters to me." Respondents agreed that African-Americans are more private about what happens to their bodies. In addition, respondents expressed a belief that education about organ donation would not help African-Americans with organ donation. Interestingly, those surveyed agreed that African-Americans needed to know about the organ donation process. A statistically significant number of respondents agreed that most people would take organs from anyone.

A statistically significant number of those surveyed did not find the opinions of fellow church members to be important regarding organ donation. They also would not restrict their donations to children, nor did they feel that the race of the recipient would be of importance. The age of the recipient was also not important. There was statis-

**Table 2. Analysis of Likert Scores by Question**

Question	1	2	3	4	5	Total	Mean	SD	t	p
*5a	6	12	35	46	42	141	3.752	1.089	8.20	0.0001
*5d	11	19	42	45	22	139	3.345	1.174	3.47	0.0001
*6a	2	1	31	59	48	141	4.064	0.849	14.88	0.0001
*6c	3	5	38	47	48	141	3.936	0.967	11.49	0.0001
*6e	4	1	35	61	39	140	3.929	0.911	12.06	0.0001
†7a	58	41	26	10	7	142	2.063	1.179	-9.47	0.0001
*7b	2	0	8	49	81	140	4.479	0.738	23.70	0.0001
*7c	1	0	7	52	79	139	4.496	0.653	27.03	0.0001
*7d	2	5	27	49	57	140	4.100	0.954	13.64	0.0001
*7e	2	3	29	43	62	139	4.151	0.944	14.37	0.0001
†8a	46	55	14	9	18	142	2.282	1.321	-6.48	0.0001
†8b	71	41	17	7	4	140	1.800	1.019	-13.93	0.0001
†9a	32	53	38	18	2	143	2.336	1.021	-7.78	0.0001
*9b	11	16	38	61	13	139	3.353	1.096	3.79	0.0001
9c	13	30	37	42	17	139	3.144	1.159	1.46	0.146
*9d	1	0	23	66	49	139	4.165	0.738	18.63	0.0001
*10a	1	0	8	67	66	142	4.387	0.676	24.44	0.0001
10c	32	28	25	28	26	139	2.914	1.654	-0.70	0.488
†10d	42	26	37	20	15	140	2.571	1.329	-3.81	0.0001
10e	13	21	55	37	14	140	3.129	1.083	1.41	0.162
*11a	3	7	41	63	27	141	3.738	0.907	9.66	0.0001
11b	44	62	28	4	1	139	1.964	0.833	-14.66	0.0001

\* Indicates the mean was statistically greater than 3.0.

† Indicates the mean was statistically less than 3.0.

tically significant disagreement with the statement, "African-Americans don't believe in giving their organs." The respondents denied any concern that a White person would get their donated organs before an African-American would.

The respondents did not tend to form a consensus in either agreeing or disagreeing with three statements: 9c: "I seldom hear about African-Americans getting an organ transplant," or, 10c: "I am convinced that important people get organs first," and, 10e: "An African-American is less likely to get donated organs if they need them."

### Discussion

Unlike previous studies, these participants lived in California. Other similar studies in the past were done using African-American participants from east of the Mississippi. It appears that African-Americans on the west coast do not share the same concerns related to organ donation as their counterparts do in other regions of the country.

While Glasgow's (2007) participants were concerned about the approval of others, the age of the recipient (people over 80 years were considered to be at the end of life, therefore in less need of a transplant); and, mistrust/racism, these concerns were not barriers for the California respondents. Prior studies seemed to indicate that participants were concerned about organ donation being in conflict with their religious beliefs. Conversely, the California participants did not believe that fellow parishioners' opinions regarding organ donation were of importance. The fact that this sample seemed knowledgeable about transplant possibly enhanced attitudes toward donation. Across the board, respondents seemed to appreciate the altruism involved in organ donation. They felt good about helping others.

### Limitations of the Study

The survey was distributed to members of a professional nursing organization. It is possible that health-care professionals may have encountered the recipients of organ

donation over the course of their career, thus making them more accepting of the idea of organ donation. More than half of the respondents reported having a bachelor's degree or higher. It is possible that more educated participants are more knowledgeable about organ donation. Many of those surveyed were friends, family, or associates of the study's primary investigator, who worked as a transplant coordinator in the past. It is unknown what impact, if any, this had on the respondents. The topic of organ donation is not widely discussed in the African-American community, but the respondents were supportive of the researchers' efforts.

### Conclusions

The demand for donor organs in the African-American community continues to rise. The disproportionately low number of African-Americans willing to donate leads to a problem of supply and demand. In order to understand this phenomenon, the barriers to organ donation must first be identified. This study illustrates the differences in the opinions of California's African-Americans compared with African-Americans in the Midwestern or the southern parts of the United States. Further research, perhaps qualitative, is needed to understand these regional differences, such as why Californians are not concerned with the opinions of others. Future research might also address the incongruity in the statements: "I know/would like to know about the organ donation process," and, "Education about organ donation will not help African-Americans donate organs." Finally, further study is needed to develop and implement interventions that will increase the intention of African-Americans to donate.

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