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Jennifer Yvonne Cannon

*Eastern Illinois University*

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Are You In or Out?

Qualitative Study on Factors Associated With Minorities Decisions About Organ Donation

(TITLE)

BY

Jennifer Yvonne Cannon

THESIS

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS  
FOR THE DEGREE OF

Master of Science: Family and Consumer Sciences

IN THE GRADUATE SCHOOL, EASTERN ILLINOIS UNIVERSITY  
CHARLESTON, ILLINOIS

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### **Abstract**

The United States Department of Health and Human Services (USDHH; 2011) has declared that the need for organ transplant in minorities is disproportionately high compared to Caucasians. Of the minority groups represented in the United States, African-Americans are the largest group in need of organ transplantation (USDHH, 2011) and, this group spends more time on the donor organ waiting list than any other minority group (Moore, 2007). The purpose of this study was to explore what factors affect organ donation decision making for college students from ethnic minority groups. In addition, the study looked at mistrust in the medical community and stigmas associated with organ donation.

A total of seven African-American undergraduate college students from a Midwestern university participated in a focus group to explore barriers to organ donation. Results showed that fear of dying, mistrust of the medical establishment, lack of family communication, and a lack of education about organ donation were factors that contributed to the organ donation decision making process for ethnic minorities. A major stigma associated with organ donation was in the event of a medical emergency, medical personnel would end an organ donor's life early if an organ was needed. The findings from this study can provide a foundation for future research in this area, inform educators and policymakers, and help organ donation organizations cater their recruitment strategies.

### **Dedication Page**

I would first like to dedicate this thesis to my lord and savior Jesus Christ. Without his grace, and mercy, where would I be? He has made all things possible for me, and without him I would not have made it this far in life.

I would also like to dedicate this thesis to my family. My mom and dad, Keisha, Melissa, Scott, Kieran and Kennedy. I love you all so much. I am so thankful to have you all in my life. I thank you all for the support.

I would also like to dedicate my thesis to Dr. Lisa Moyer. I appreciate her so much in believing in me to do a thesis. Dr. Moyer stood behind me and supported my topic from day one. I truly appreciate her hard work and time.

This thesis is also dedicated to my wonderful thesis committee members Dr. Shelia Simons and Dr. Jacquelyn Frank. I appreciate these women so much, and I am so thankful to have their support in my journey in graduate school.

**Table of Contents**

Introduction.....5  
Review of Literature .....8  
Methodology.....20  
Results.....23  
Discussion.....31  
References.....37  
Appendices.....40

## **Chapter One**

### **Introduction**

The United States Department of Health and Human Services (USDHH) defines organ donation as “the surgical process of providing organs to be used for transplantation into another person” (USDHH, 2011, p. 4). Organ donors can be alive or deceased. Organs of either a living or deceased donor are surgically harvested and transplanted to the donor so that the recipient has a better chance of survival with a healthy organ replacement. Deceased (donors) must have suffered brain death. Organs that can be donated include: liver, lungs, kidney, pancreas, heart, intestine, bones, skin, heart valves and veins (USDHH, 2011). Living donors can donate a kidney, liver, lung, eyes (USDHH, 2011). Anyone can choose to become an organ donor, provided they are healthy (e.g. no cancer or systemic infection) and they are HIV negative.

The need for organ transplant among ethnic minority populations is disproportionately high compared to Caucasians. Of the minority groups represented in the United States, African-Americans are the largest group in need of organ transplantation (USDHH, 2011) and, this group spends more time on the donor organ waiting list than any other minority group (Moore, 2007). This study will specifically focus on ethnic minority college students and organ donation.

#### **Statement of the Problem**

There are over 100 million organ donors in the U.S., but this is still not enough as 18 people die every day waiting for an organ (USDHH, 2011). The USDHH (2011) has declared that the need for organ transplant in ethnic groups is disproportionately high compared to Caucasians. Health conditions such as high blood pressure or diabetes in



ethnic minority groups translate into a high need for healthy organ donors. Race and ethnicity do not affect the matching of organs; however, people of the same race/ethnicity are better matches for each other in consideration of blood types and tissue markers (USDHH, 2011).

While there are numerous reports available through the Department of Health and Human Services indicating that minorities are underrepresented as organ donors and recipients, there is little to no research determining why this is the case. Studies have shown that family beliefs and myths about organ donation can affect an individual's choice to become a donor (Smith, Kopfman, Lindsey, Yoo, & Morrison, 2004), but few studies have looked exclusively at how race and ethnicity intersect with the decision to become a donor. It is hypothesized that the knowledge of unethical treatment from the government in the past towards ethnic minorities and other vulnerable populations will be a key factor in the donor decision for ethnic minority groups.

### **Purpose of the Study**

The purpose of this study is to explore what factors affect ethnic minority college students' decisions about becoming organ donors. Since little to no research exists on this topic, the findings from this study can be used to build a theoretical foundation, aid in the development of stronger recruitment programs to increase organ donation among ethnic minorities, and inform policymakers about the needs associated with the recruitment of organ donors.

The study will use a qualitative research design to explore the following research questions:

1. What factors affect ethnic minorities' decision to become an organ donor?
2. How does trust in the medical and research establishments affect decisions about becoming an organ donor?
3. What stigmas are associated with ethnic minorities decisions about organ donation?

### **Terminology**

*Ick Factor*- The basic disgust of organ donation (Smith, S. W., Kopfman, J. E., Lindsey, L., Yoo, J., & Morrison, K, 2004)

*Living Donor*- The donor has donated an organ from the their living body, usually done in family members and as a kidney donation (United States Department of Health and Human Services, 2010)

*Holocaust*- The mass slaughter of European citizens during 1933-1945 (Merriam-Webster, 2011)

*Ethnicity*- Collectivity within a larger population having real or assumed common ancestry, memories of a shared past, and a cultural focus upon one or more symbolic elements which define the group's identity, such as kinship, religion, language, shared territory, nationality or physical appearance (Bulmer, 2006)

*Race*- This thesis uses the U.S. Census Bureau's definition of race. The U.S. Census Bureau defines race as a combination of categories that include, racial, national origin, and/or sociocultural backgrounds (United States Census Bureau, 2012)

*Ethnic minority*- A diverse set of populations and subpopulations that can be classified as "non-white" according to the U.S. Census Bureau (Kumanyika & Grier, 2006)

## Chapter 2

### Literature Review

#### Mistrust in the Medical System

Mistrust in the medical system is not a new concept. Throughout U.S. and world history, humans have been used in medical and research studies without informed consent. This has been particularly true for ethnic minority populations. In the time of World War 1 and the Sino-Japanese War, Japanese military personnel conducted experiments that were later labeled “Unit 731.” Under the leadership of Shiro Ishii, the Japanese military targeted Chinese, Koreans, and American prisoners of war to undergo human experiments (Watts, 2002). During these trials, humans were subjected to autopsies while alive without anesthesia. This was done to explore human organs and blood loss (Watts, 2002). Victims were also subjected to weapon testing where weapons were thrown at humans to determine how long a human could survive after a weapon had been thrown at them. Participants were also subjected to germ warfare, where they were injected with diseases and viruses to determine “the validity of germ warfare” (Watts, 2002). More than 10,000 people died as a result of the human experiments that occurred in Unit 731 (Watts, 2002).

In 1997, several survivors and their families sued the Japanese government and demanded an apology from the government (Watts, 2002). After several court hearings the plaintiffs received \$10 million dollars (US \$8400) as reparation for Unit 731. Unfortunately, the dehumanization of humans has occurred throughout history in many other countries all over the world.

During the Holocaust, “the mass slaughter of European citizens during 1933-1945” (Merriam-Webster, 2011), minorities (Jews, African-Americans, homosexuals, and gypsies) were forced to engage in unethical medical experiments (Bogod, 2004). Under the leadership of Adolf Hitler, members of these various minority groups were sent to concentration camps where they endured torture in the hopes of broadening medical research. Minority prisoners at concentration camps were forced to participate in the Nazi Hypothermia Experiment (Bogod, 2004). Participants were strapped down and thrown into ice cold water while physicians measured and charted their heart rate, level of consciousness, and their amount of shivering (Bogod, 2004). As a result of this experiment, 300 prisoners froze to death. The study was used to develop a plan to prevent Nazi soldiers from freezing in the Northern Sea against their enemies. In addition to hypothermia experiments in concentration camps, the Nazi medical staff forced prisoners into compression camps (Bogod, 2004). While in compression camps Nazis would strap prisoners to chains in a low pressure chamber and stimulate to increasing altitudes (Quinn & Shuster, 2004). Approximately 200 prisoners were put into compression camps for long periods of time. The purpose was to develop survival plans for Nazi military pilots jumping from high altitudes (Quinn & Shuster, 2004).

The unethical medical cases that occurred during the Holocaust serve as serious and horrifying examples of unethical treatments of research participants. The very use of prisoners in the Nazi concentration camps in medical research is problematic as the prisoners did not have a choice about participation. However, this type of treatment was not an isolated event.

In 1932, researchers at Tuskegee University implemented a study about African-Americans and the syphilis virus. Researchers sought to explore the natural course and latent stages of the syphilis virus in African-Americans (Kennedy, Mathis, & Woods, 2007). The study included 400 African-American sharecroppers from Macon County, Alabama that were infected with syphilis. Participants were told they were getting treatment for “bad blood” a term often associated with several complications including fatigue, anemia, and other medical diseases (Kennedy et al., 2007). Compensation for participation included free meals, medical treatment, and burial expenses. Researchers did not obtain informed consent from participants in the study, nor did they inform the participants of the true nature of the research.

During the course of the study, conditions associated with the disease worsened in participants. In 1947, when Penicillin, the drug of choice for syphilis treatment, became available, participants of the study were not told about the treatment or given the option to receive penicillin. Researchers also failed to inform participants that they could drop out of the study at any time without consequences. It was not until 1972 that the United States’ Public Health Service ended the study after uproar in the Associated Press caused an investigation. The investigation that followed revealed that 120 African-American men had died from syphilis. In addition, 40 participants had passed the disease onto their wives and 90 had children born with congenital syphilis.

It is highly likely that the Tuskegee Study has affected how African-Americans view the government and medical establishments. The very idea that doctors and medical staff would withhold treatment is thought to be a major concern among African-American and other ethnic minority communities (North Carolina State University

Department of Sociology and Anthropology, 2010). It is likely that unethical research practices have had a long-lasting effect on participation in medical research studies by members of ethnic minority communities.

Davis, Green and Katz (2012) examined the effects of the Tuskegee study experiment on minority participation in medical research. In the qualitative study, researchers designed a two session focus group focusing on participants' willingness to cooperate in medical research. The research sample consisted of 252 African-Americans between the ages of 19 through 45. Results concluded that the majority of the participants ( $n = 175$ ) were knowledgeable about the Tuskegee Syphilis study, and were less likely to participate in medical research. Researchers reported that many participants stated that they did not want to be used as medical "guinea pigs" (Davis et al., 2012). In addition to the Tuskegee syphilis study, researchers also believe the Willowbrook State School study is one of importance regarding ethics and the treatment of minority and/or vulnerable populations.

The Willowbrook State School research studied hepatitis in children with mental retardation who were living together in a group home setting (Miller & Grady, 2001). Krugman and colleagues (as cited in Miller & Grady, 2001) obtained informed consent from the parents and legal guardians of the children that were included in the study. The study was designed to "study the circumstances at which the disease occurred and the effect of gamma globulin, in an attempt to induce passive active immunity" (Miller & Grady, 2001, p. 14). Krugman and colleagues deliberately fed children the feces of children that were infected with hepatitis to monitor the progression of the disease in the study's sample. One group of children served as the experimental group and the

participants were given protective antibodies against the virus, while the other group (control group) was not given protective antibodies. The researchers examined the immunity and progression of the disease in both groups. The findings showed that the children who contracted the virus from the sample experienced different strands of the virus, and immunization served as a prevention mechanism for the control group. To date, the effects of this particular study have not been linked to minority Americans' willingness to participate in research studies; however, it seems likely that the study would add to the mistrust of researchers.

Mistrust in the medical establishment was evidenced in the research study of Henrietta Lacks, who was a tobacco farmer whose cells were used by physicians without her or her family's knowledge (Lucey, Nelson-Rees & Hutchins, 2007). Henrietta was seen at John Hopkins hospital in 1951 for a mass tissue growing outside of her cervix. After dying in the hospital the same day of entrance a biopsy of the tissue was taken from Henrietta without her family's consent. Tissue from the growth was later mixed with a special formula creating the ability of cells to live outside of the body in a confined cell periodic dish. Before Henrietta's cells were used doctors were not been able to keep cells alive outside the body for longer than a couple of hours (Lucey et al., 2009). The usage of Henrietta's cells has been renamed as the HeLa cells. These cells have been reproduced and multiplied in medical research for cancer, development of polio vaccine, manufacture of drugs for herpes, influenza and other drugs, and vitro fertilization drugs (Lucey et al., 2009). It was not until years later that Henrietta's family was informed of the use of their mother's cells.

The experiments of the Holocaust, the Tuskegee study, the Willowbrook study, and Henrietta Lacks's unapproved use of cells birthed mistrust in the medical establishment among ethnic minority populations. Unethical practices on behalf of the medical establishments and researchers have likely lead to a general distrust surrounding organ donation among all donors, but particularly among ethnic minorities.

### **History of Organ Donation and Harvesting**

The beginning of organ donation dates back into archaeological and historical records. Researchers Howard, Cornell, and Cochran (2012) from Life Quest Organ Recovery explored the chronological lifeline of organ donation and transplant. Between 1300 BCE and 2500 BCE, the Hindu culture practiced removing skin from individuals' faces and placing it onto the buttocks area as punishment of a committed crime. In Hindu culture, ancient gods, beasts, and heroes are shown to have organs and animal parts. In Chinese culture, an ancient doctor named Pien Chiao transferred hearts of those that appeared strong in spirit into the bodies of those deemed weak in spirit (Howard et al., 2012). Legislation for organ transplant occurred in the year 1540 for England. A legal act allowed surgeons practicing in England to gain access to bodies of deceased criminals to expand research on human anatomy and organ sharing.

Mosimann (2011) researched organ transplantation of executed prisoners in correctional facilities in the 1600s in the United Kingdom. Mosimann reviewed data charts and memos from that time period to determine if there was evidence of unethical organ transplants within a five year time span (1616-1621). Results showed that 150 executed prisoners 50% ( $n = 75$ ) had their organs used for organ donation, without the prisoner's consent. Ethnicity demographics of the prisoners were not reported for this



study; however data indicated that all participants used in the organ transplants were male.

In 1869, United States surgeons performed the first skin transplant (USDHHS, 2012) and in 1954, physicians performed the world's first kidney transplant on twin brothers (Zink & Wertlieb, 2006). The kidney transplant resulted in the twin recipient successfully receiving a kidney and living another eight years. The year 1967 saw the first successful heart transplant in Africa. A year later, France incorporated a law entitled the "opt-out policy" which stated that upon death a person was presumed to be an organ donor, unless their families contested (Zink & Wertlieb, 2006).

In 1968, the first organ procurement organization (OPO) was based in Boston. At this point in time, more research had been conducted and it was concluded that Cyclosporine (medication used to decrease rejection of organ in person's body) worked to suppress the immune system and increased the likelihood of an organ being accepted (Sque & Payne, 2006). The Food and Drug Administration approved Cyclosporine in 1983 in the hopes of aiding the success rate in organ transplants. Within that same year, the first successful liver and heart transplants were performed in the United States.

Surgeon General Everett Koop facilitated the first seminar on organ transplant in the hopes of educating doctors and the medical field on organ donation. It was not until 1991 that the first recruitment seminar was organized. A surgeon named Antonia Novella conducted the recruitment workshop to encourage U.S. citizens to become organ donors. Prior to Novella conducting the workshop, surgeons in the U.S. were successfully completing lung and intestine transplants on an ongoing basis (Sque & Payne, 2006). In 1998 and 1999, the first hand transplants were successfully completed in France and in

the U.S. respectively. In 1999, the U.S. implemented the Organ Donor Leave Act, which allowed federal employees to receive monetary compensation and enlist as living organ donors (United States Personal Management, 2011). In 2001, “the number of living organ donors exceeded the number of deceased organ donors for the first time” (Sque & Payne, 2006, p.45). The Department of Health and Human Services took the initiative to aid in the increasing number of organ donors in 2002, by directing a documentary entitled “*No Greater Love*” which showed the importance and developments in organ donation (United States Department of Health and Human Services, 2011). In 2009, the National Kidney Foundation launched a campaign entitled “End the Wait,” in hopes of increasing kidney donations (National Kidney Foundation, 2010).

As can be seen by this brief history, physicians and other healthcare administrators have tried to increase the number of potential organ donors through creative initiatives. However, there is still a need for more organ donors as many patients expire while waiting to receive the organs they need to survive. An important piece in the effort to recruit more donors would be to examine why people refuse to become organ donors.

### **The Decision to Become an Organ Donor**

People who are HIV positive have active cancer or a systemic infection cannot be organ donors. If those stipulations do not apply to a person they can choose to become an organ donor. The first step is to register as a donor in the state’s organ donation registry. All states adhere to the mandate of donor consent, which is “an individual’s legally binding decision to become an organ/tissue donor” (USDHHS, 2011, p.1). Once a person commits to the registry, they are declaring a legal decision that they want to donate their

organs after death. By making this declaration, a family member or next of-kin cannot overturn their decision. In the past, family members or next of-kin were able to refuse donation of organs if an individual was deemed incompetent, or if family members disapproved of organ donation (USDHH, 2011). However, as of 2006 this law is no longer applicable.

### **Barriers Associated with Organ Donation**

The need for organ donation continues to increase (USDHH, 2012). Denvir and Pomerantz (2009) studied barriers to organ donation among a sample of 180 male and female college students. Denvir and Pomerantz conducted interviews with the participants and asked them to provide an audio recording of their family's discussion on organ donation. The findings indicated that one of the barriers to organ donation was the fear that medical personnel would withhold treatment as a means for harvesting an organ from an able body.

Sirios, Sears and Marhefka (2005) studied adolescent's attitudes, knowledge, and perceptions on organ donation compared their parental units. A total of 137 adolescent and parental units were surveyed on their likelihood to become organ donors. Results showed that adolescents had greater knowledge of organ donation; however older adults were registered to be organ donors.

Another barrier discovered in the analysis was the participants' fear of medical personnel providing limited treatment. Participants thought that medical staff might not work as hard to revive them if they were identified as an organ donor. The final barrier was that death might be declared prematurely by medical personnel if they knew the

patient was a donor. The findings from this study highlight the types of fears potential donors have about medical personnel's role in patient care in the event of organ donation.

O'Corroll, Foster, McGeechan, Sandford, and Ferguson (2011) studied the emotional responses of the general public of potential organ donors. O'Corroll et al. set out to investigate the phenomenon called the ick factor, "a basic disgust and reaction to the idea of organ donation" (p. 236) to determine if it was an emotional barrier to organ donation. The findings revealed that participants-viewed organ donation as morally wrong, and unethical to reuse organs of the deceased. Many participants stated that the idea of putting the organs of a deceased human into another human was emotionally wrong and disgusting. These reasons were cited as influential when making the decision to become an organ donor.

Smith, Kopfman, Lindsey, Yoo, and Morrison (2004) explored the role that family communication can play in the decision to become an organ donor. Smith et al. examined family communication in families that did or did not include an organ donor. A total of 460 participants ranging between the ages of 18 to 75 served as the sample. Data was collected through focus groups and interviews. Findings revealed that the families that had not discussed organ donation were more likely to disregard their loved one's wishes to become an organ donor.

Smith et al. (2004) emphasized the importance of sharing the desire to become an organ donor with close family members. Even though it is illegal for family members to override the decision to donate made by a deceased individual, it is clear from the research that family members' feelings about organ donation affect whether or not individual family members choose to become organ donors. Thus, it is important for all

families to have a discussion about organ donation so that everyone is aware of each other's feelings about the topic. There are already a number of barriers to organ donation, so eliminating the ambiguity surrounding organ donation in the immediate family is an important first step towards removing barriers.

### **Race/Ethnicity and Organ Donation**

The United States Department of Health and Human services has declared that the need for organ transplant in many minority groups is higher than in Caucasian/white individuals. High incidences of conditions such as high blood pressure or diabetes among ethnic minority groups are the main reason for the higher need (USDHH, 2011). Race and ethnicity do not affect the matching of organs; however, people of the same race/ethnicity are better matches for each other in consideration of blood types and tissue markers. As of June 2011, The Department of Health and human Services reported that minorities represent 61% of patients waiting for an organ transplant. Of the ethnic groups represented in the United States, African-Americans are the largest group in need of an organ transplant (USDHH, 2011). Unfortunately, Moore (2007) reported that only 22% of African-Americans on the kidney donor organ waiting list actually ever receive a donor kidney. Moore also noted that African-Americans spend more time on the waiting list compared to other ethnic groups.

The need for organ donors is high among all minority groups, but particularly for African-Americans. However, barriers like fear of the medical establishment and/or government can interfere with one's decision to become an organ donor. This study will look at what factors prevent college students from signing up to become organ donors.

More specifically, the study will use a qualitative research design to answer the following research questions:

1. What factors affect ethnic minorities' decision to become an organ donor?
2. How does trust in the medical and research establishments affect decisions about becoming an organ donor?
3. What stigmas are associated with ethnic minorities decisions about organ donation?

## **Chapter 3**

### **Methodology**

The purpose of this research was to examine decision making regarding organ donation among college students from ethnic minority groups. A qualitative research design was used to collect data from participants. Qualitative research design is useful when a topic has been understudied as it allows the researcher to collect richer and more in-depth information from participants compared to quantitative methodology (Golafshani, 2003).

### **Instrumentation and Procedures**

A focus group was held to explore the research questions in the current study. Participants from ethnic minority groups were recruited through a snowball sampling procedure at a public Midwestern university. Snowball sampling was used in order to ensure that participants were from a variety of organ donors and non-donors. The researcher developed a structured list of questions and prompts to ask participants during the focus group. The questions/prompts included the following:

1. Please describe your decision to become an organ donor, or to refuse to become an organ donor.
2. Describe what you know about the mistreatment of ethnic minorities in research throughout history.
3. How does trust in the medical and research establishments affect your decision about becoming an organ donor?
4. Is your family aware of your decision to become an organ donor?
5. What did your family talk about in regards to organ donation?

6. How did your family's communication (or lack of) about organ donation affect your feelings about organ donation?
7. What stigmas do you feel are associated with African-Americans decisions about organ donation?
8. Why do you think that minorities are underrepresented among organ donors?
9. Is there anything else that you think I should know about African-Americans and organ donation?

The researcher recruited participants by attending minority centered registered student organizations at EIU. These organizations included Minority Student Health, Black Student Union, African Student Association, Megiste Arte Christian Fraternity Incorporated and Elogeme Adolphi Christian Sorority Incorporated. Food was used as an incentive for participation during the focus group. Upon completion of the focus group, participants also had the opportunity to win a \$25.00 gift card.

Once participants were identified, informed consent was obtained (see Appendix A). At the focus group, participants were asked the questions listed above and encouraged to elaborate on their responses when deemed necessary. A script was prepared to help facilitate the focus group (see Appendix B). The researcher used an audio recorder so that the responses from the participants could be transcribed word-for-word after the focus group concluded. Although audio footage of the focus group was recorded, participants' names or physical appearance was not documented. The focus group was scheduled for approximately 90-120 minutes.



There were not any foreseen risks or harms to the human subjects in this study. The focus group was held in a private room that was booked in advance by the researcher's thesis advisor in the Martin Luther King university union. Only the researcher was present during the focus group so that the participants felt comfortable disclosing information about organ donation. The researcher was African-American, and it was believed that this would help put participants at ease.

### **Reliability and Validity**

The existing literature on barriers to organ donation was used to inform the researcher in the development of the structured focus group questions and to provide a basis of face validity for the instrument. In addition, members of the faculty in the School of Family and Consumer Sciences at EIU reviewed the questions for an additional confirmation of face validity. The instrument was pilot tested prior to data collection to gather feedback and make any necessary changes. The pilot study also helped to provide support of face validity, and thus the reliability of the instrument as it is difficult to establish true reliability of a measure in qualitative research (Golafshani, 2003).

### **Data Analysis**

Once the data from the focus group was transcribed, the researcher sorted the responses into common themes. Themes were then named and direct quotes were used to illustrate the types of responses common to the themes.

## Chapter 4

### Results

#### Results and Discussion

The purpose of this research was to examine factors that affected the decision to become an organ donor among college students from ethnic minority groups. A qualitative research design was used to collect data from participants. The three research questions included:

1. What factors affect ethnic minorities' decision to become an organ donor?
2. How does trust in the medical and research establishments affect decisions about becoming an organ donor?
3. What stigmas are associated with ethnic minorities' decisions about organ donation?

**Description of the sample.** It was the principle investigator's intent to recruit participants from different ethnic minority groups in order to have a diverse sample of ethnic minorities. However, only African-American participants were able to be recruited for the study; thus, the findings are framed within the African-American community, as opposed to "ethnic minorities." This included rewording the research questions in the results and discussion sections, so that they referred only to African-Americans, rather than ethnic minorities. This was done to comply with the principle investigator's thesis committee's request at the defense.

The sample for this study consisted of seven undergraduate college students, currently enrolled at a public university located in the Midwest. There were three females and four males in the focus group. The ages of the participants ranged from 19

years to 24 years old. All participants self-identified as African-American. Four participants indicated that they were not organ donors, while the remaining three indicated that they were registered organ donors.

**Focus group sessions.** Participants' responses from the focus group were categorized using a thematic content analysis. Responses from the focus group were transcribed word for word and then examined for commonalities. The responses were reviewed numerous times and then general themes were identified to answer each research question. The themes that were developed are presented and discussed within the organizational framework of the research questions.

### **Findings Sorted by Research Questions**

#### **What factors affect African-Americans' decision to become an organ donor?**

The first research question examined factors that affected African-Americans' decision to become an organ donor. Participants were asked to "please describe your decision to become an organ donor or refusal to become an organ donor." However, in order to capture the full essence of the focus group data, all of the responses were examined for all of the questions/discussion. After careful review, the principle investigator identified five themes that could be classified as factors that affect the decision to become an organ donor. The five themes included the lack of or amount of education about organ donation, generalized fear, family communication, religious beliefs/spirituality, and agreeing to become an organ donor implied that one was suicidal.

The first theme concerned the lack of or amount of education about organ donation. One participant stated "Have not done enough research, do not know about it. But I'm willing to learn about it." While another participant said "People are educated on

what they want to know, this issue is not brought up us [sic] so how would we know about this. Yes, minorities could show interest in this issue, but it's not in front of our faces, like other stuff."

The second theme centered on a generalized fear that medical staff would not intervene to save the life of a known organ donor. For example, one participant noted

When I was younger, one of my parents told me if you get into an accident or become non responsive, the paramedics will not try to save your life if you are an organ donor. They will not try to exalt all measures to keep you alive. They will speed up your death to get the organs.

Another participant indicated that "I do not want to die, and by filling out the paper I am saying that I want to die." Still another said "My friend died, got shot and his family had him on life support. We know that every procedure or strategy was not used because he was an organ donor." The fear of having one's life ended prematurely because they were registered organ donors was pervasive throughout the focus group discussion.

The third theme that emerged focused on family communication about organ donation. All participants were asked directly about family communication around the decision to become an organ donor or organ donation in general. One participant stated

Because we never talked about organ donation in my family I assumed that it was bad, and something that should not be done to my body. As everyone discussed today, I think about if I was an organ donor. Would I get that organ, or would someone in my family get that organ. I know my parents aren't organ donors.

Another participant noted that the question “was never brought up, so I went and did it.” Still another indicated “...it was not brought up, but I remember one time the commercial came on in when I was watching TV with my family. And we all just had a blank stare on our face, from the information about organ donation shown on the commercial.”

The fourth common theme found for factors that affect organ donation concerned religious beliefs/spirituality. One participant stated “The Bible does not talk about organ donation, so I believe it would not be shown as being a bad thing.” Still another said that “...Jesus would not be like naw [sic] you cannot save this life because I gave you all these organs...”

The fifth factor that revealed itself in the focus group was the idea that agreeing to become an organ donor implied that one was suicidal. For example, one participant said “Parents told me not to talk about that, because that was a sign that I wanted to die, and that works with suicide.” Another respondent stated that “... I do not want to die, and by filling out the paper I am saying that I want to die.”

**How does trust in the medical and research establishments affect decisions about becoming an organ donor?** The second research question examined how trust in the medical and research establishments affects decisions about becoming an organ donor. Three themes surfaced in the data after careful review. The three themes included: A negative perception of the medical establishment as a business, historical unethical treatment by the medical industry, and communication with medical personnel.

In the first theme, it was apparent that participants were concerned with how money affected organ donation and how hospitals treat patients with money before those without. For example, participants mentioned the 2002 movie “John Q,” in which a young boy was denied an organ transplant by a medical establishment, because his parents did not have adequate insurance. One of the respondents argued that,

If you do not have a lot of money to get on the top of the organ donor list then you will not get that organ that is needed. Like in the movie John Q, they did not have the money, so the dad had to do what he had to do.

Money is what is going to make people get on the list and on the top of the list.

Another participant said

The medical establishment is there to help us, but ultimately it is there to be a business. So they are in the money making business, just like any other thing is in the money making business. So like he said money is going to you get that organ.

A second theme associated with trust and mistrust in the medical establishment concerned the historical studies of mistreatment in medical establishments. One participant mentioned

When I was younger, I was at the hospital waiting for a check and a college student doing research asked my mother and I if we could be a part of her research. She told me that if I participated I would receive a McDonald’s happy meal gift card. The lady got a swab of my spit from

my cheek then put my swap in a tube. I do not know where the tube went after that. Which reminds me of the HeLa cell. Lady went in for a pap smear. Then doctors took her cells, and DNA sample. She did not sign off for her cells to be used; no informed consent was taken from her family.

Doctors reproduced her cells. HeLa cells come from her name.

Companies have made billions of dollars off her cells. Her family has not received any compensation or acknowledgement from using their mother's cells.

Finally, the third theme that became apparent in the focus group concerned how medical personnel communicate with patients, particularly ethnic minorities. One participant stated that "... medical professionals do not know how to talk to people. I would not put it on paper that I want to become an organ donor." Another participant replied that "I noticed in the medical establishments, the jargon that doctors use is not always understandable. I do not feel comfortable knowing that doctors can talk in any manner and minorities not ask questions. As minorities we have to ask the right questions."

**What stigmas are associated with African Americans' decisions about organ donation?** The third research question examined stigmas associated with African American college student's decisions about organ donation. Three themes materialized from the data concerning stigmas associated with ethnic minorities. These themes included: Concerns about dying early, the perpetuation of myths about organ donation in general and the lack of resources for ethnic minority communities.

A big concern that was voiced multiple times by focus group participants was centered on the notion that organ donors are killed by medical personnel for the harvesting of their organs. One focus group member noted "...Heard doctors do not take time on you. Like if you are in a car accident, it's skeptical." While another participant said "...They will speed up your death to get the organs." Perhaps the most alarming was the comment by a respondent that posited "Well, like I said I thought they will kill you faster if you are an organ donor, and the doctors will not perform everything that is needed to be done for you."

The second theme that was associated with stigmas around organ donation was the perpetuation of myths about organ donation. Many of these myths have already been discussed above, but one statement by a participant truly illustrates this theme: "Well I think the misconception that you are going to die quicker if you are a organ donor floats a lot in the minority community." Many other examples are listed above – it was obvious that the focus group participants felt like medical personnel would commit murder in order to harvest organs, which is a myth that has been perpetuated in many communities when it comes to organ donation according to participants' responses.

Finally, a third theme that could be classified as a stigma was focused on how the availability of resources affects African-American communities, and ultimately organ donation. For example one participant declared that, "...if the resources were in our community, would take use of it [sic]. We settle for the free clinic available, yet we will walk around in the fliest Jordans [sic] and clothes while our teeth look crazy." Another respondent stated that



Well money is going to make the resources available in the community. If the money is not there in the community, then the resources cannot be available. Whether people believe it or not once, in minority communities the money is not there.

The results from this qualitative analysis indicate that the African-American participants would be more inclined to become organ donors if accurate information was readily available on the topic. Information that needs to be mentioned to potential donors during recruitment includes the benefits of organ donation, the need for organ donors, and the process of becoming an organ donor. Once accurate information about organ donation is more readily available, family communication about organ donation will be more likely to take place. Families are an incredible influence on individual decision making about organ donation, so it is essential that families are provided the tools needed to communicate about this topic.

The data also indicated that trust within the medical establishment needs to be reestablished based upon past history. It is believed that once individuals from African-American communities understand the process of organ donation and that most of the information that they have heard about organ donors is untrue, more people will step up and agree to donate their organs.

## Chapter Five

### Discussion and Conclusion

The original purpose of this research was to examine factors that affect the decision to become an organ donor among college students from ethnic minority groups. However, since only African-American students participated in this study, the results and discussion will focus exclusively on the African-American community. Very little research has been conducted on this topic to date, yet research shows that African-Americans are less likely to donate their organs than their Caucasian/white counterparts (United States Department of Health and Human Services, 2009). The results collected from this study will hopefully provide a foundation on this topic for future researchers and practitioners. Overall, the current study revealed that the African-Americans who participated in this research would like to know more about organ donation; however, there seems to be a lack of education provided to this audience.

The results also showed that although the participants in this study did not recall specific examples of historical abuse in ethics and trust within the medical establishment, the mistrust in the system did exist, it was just evidenced through general misconceptions and myths about organ donation. This distrust is passed on to children through their families and through other members of the community. For example, many of the participants reported that they had “heard” that organ donors’ lives would be cut short if an organ was needed. In fact, the fear of having one’s life ended prematurely if medical personnel discovered that their patient was an organ donor was mentioned frequently throughout the focus group. Clearly this is a topic that needs to be addressed if more organ donors are needed. What is unclear at this point in time is whether this fear is more

likely to occur among other ethnic minority communities in addition to African-American communities, as compared to Caucasian/white communities.

During the focus group participants continuously brought up the issue of how money affects organ donation. Participants thought that money could buy a patient's way to the top of the donor list or that it could actually buy an organ. Participants also brought up the perception that the lack of resources in low income areas affected minorities' decisions about becoming organ donors. For instance, it was noted by one participant that if there were more resources in low income communities more education and information about organ donation would be more accessible, which would in turn result in more organ donors.

Aspects of spirituality were also addressed in the focus group. Participants stated that although their religion did not prohibit organ donation, they believed they were created by God with all of their organs, so they should be taken out (die) with all of their organs. Those who were organ donors stated that because their religion did not mention organ donation, then they assumed that it was okay.

Family communication was a common thread in the discussion regarding factors that affect the decision to become an organ donor. This finding is consistent with the existing literature on organ donation among white, middle-class families. For example, in the current study participants noted that they learned about organ donation and even myths about donation through family members. In the literature reviewed for this thesis, results from previous empirical studies showed that individuals from white, middle class families are less likely to become organ donors if their family did not discuss organ donation. However, the results from the current study showed that the African-American

participants' families engaged in negative communication about organ donation, particularly perpetuating myths about dying prematurely. It is unclear at this point whether "no news is good news," meaning, is it better for families to avoid discussing organ donation if all that they have to say is negative? This is something that should be pursued in future research.

Mention of mistrust in the medical establishment was prevalent throughout the review of literature for this thesis but the way that it was mentioned in the focus group from this study was in a more indirect manner. While one participant specifically mentioned the HeLa cell study, which was a prime example of the medical establishment conducting unethical research and/or not taking the steps to obtain informed consent from participants, this was the only specific example cited by focus group members. The unethical treatment of ethnic minorities in research studies throughout history obviously affected the African-Americans in the current study, but the manner in which it was discussed pointed out that historical treatment of ethnic minorities has helped to form the myths and misconceptions associated with organ donation today. Thus, while family members did not necessarily make specific mention of historical examples, the common thread of mistrust revealed itself through the myths that continue to get passed down to generations. For example, the focus group participants indicated a generalized fear of having their life ended early if they were registered organ donors. Although this does not specifically reference historical mistreatment, the results are the same as any negative beliefs or publicity about organ donation causes the perpetuation of myths and misconceptions.

Previous literature and the findings from this study insinuate that when medical establishments withhold information from participants at any point in time, it can have a negative effect on the recruitment of organ donors among future generations. When withholding of information occurs, it means that potential donors are not accurately informed about the benefits of organ donation, which can certainly have an effect on deciding to become a donor. The results from this study also made it clear that education is a primary factor in the process of moving forward in the recruitment of organ donors from African-American communities. Educating members of the African-American community about organ donation, and educating medical staff on how to talk about organ donation to members of all ethnic minority groups is vital in increasing organ donation within ethnic minority communities

### **Limitations**

There were several limitations in the current study. One limitation was the small sample size which made the data difficult to generalize to all African-American college students. However, in the search for a deeper understanding about organ donation, the decision was made by the principle investigator and her committee that a small sample size was appropriate.

Another limitation in the current study was the research design. While a qualitative design is appropriate when attempting to establish a foundation of research on a particular topic that lacks one, it also limits the amount and type of data that can be collected. Finally, the snowball sample procedure represented another limitation as the sample was not a randomized representation of the population. However, it was

necessary to use snowball sampling to ensure that enough students were recruited for the study.

### **Recommendations for Future Research**

Several recommendations are proposed by the principle investigator for future research. First, a bigger sample size should be included in future research in order to be able to generalize findings to the larger population. Future research should also focus on additional factors associated with organ donation in other ethnic minority groups in order to tease out how best to help educate all populations. Finally, comparisons among different ethnic groups should also be conducted as differences by ethnicity most likely exist when it comes to decisions about organ donation.

### **Recommendations for Practitioners and Educators**

It became apparent when analyzing the data for this research that there is a great need for increased awareness about organ donation within the minority community. The awareness needs to include the need for minorities to become organ donors as there is currently a shortage of ethnic minority donors. One of the ways to proceed with this recommendation is to dispel the myths and misconceptions that continually affect the African-American community. Although the sample size for the current research was small, one of the persistent themes among the group was the thought that organ donors risk having their lives ended early by medical personnel. Through awareness, more ethnic minorities might consider becoming organ donors. In addition, the participants were right when they noted that more resources within ethnic minority communities will lead to more accurate awareness about organ donation and hopefully, more donors. Practitioners and policymakers should consider conducting information sessions for

community members about organ donation and help communities to build better resources that deal with all family issues as everything is interrelated when it comes to decision making in families.

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**APPENDIX A: Informed consent****CONSENT TO PARTICIPATE IN RESEARCH**

*Are You In Or Are You Out?*

You are invited to participate in a research study conducted by Jennifer Yvonne Cannon and Dr. Lisa Moyer, from the School of Family and Consumer Sciences at Eastern Illinois University.

Your participation in this study is entirely voluntary. Please ask questions about anything you do not understand, before deciding whether or not to participate.

You have been asked to participate in this study because you a member of an ethnic minority group, and a student attending a Midwestern university.

- **PURPOSE OF THE STUDY**

The purpose of this focus group is to gather information regarding the factors associated with the decision to become an organ donor among college students from diverse ethnic backgrounds.

The data collected from the focus group will be used to inform Ms. Cannon's thesis and may be presented at professional conferences or submitted for publication to a professional journal.

- **PROCEDURES**

If you volunteer to participate in this study, you will be asked to engage in a focus group facilitated by Ms. Cannon. Ms. Cannon will ask the focus group participants questions concerning organ donation.

The focus group will consist of 10 people and last approximately two hours. The focus group will be scheduled around participants' availability.

The focus group session will be audio recorded for transcription purposes. When Ms. Cannon transcribes the data for her thesis, only participant responses will be recorded. Some descriptions of the participants will be used to help distinguish them from other participants, but no identification will be used. Instead pseudonyms will replace real names. Only Ms. Cannon will listen to the audio recordings in order to transcribe the data into words for analysis purposes. The audio tapes will be kept in a locked cabinet in Ms. Cannon thesis advisor's office (Dr. Lisa Moyer, an Associate Professor in FCS), which is located in 2016 Klehm Hall for a period of five years which they will be destroyed.