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## **Knowledge Deficit of Patients Regarding Organ Donation in the Primary Healthcare Setting**

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KNOWLEDGE DEFICIT OF PATIENTS REGARDING ORGAN DONATION IN THE  
PRIMARY HEALTHCARE SETTING

by

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Clinical Research Project

Submitted in Partial Fulfillment of the Requirements for the  
Degree of Master of Science in Nursing, College of Nursing and Health Sciences

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Graduate Committee Approval

The Graduate Committee of Emily Anders, Kayla Jenkins, Michelle Rainey, and  
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## DEDICATION

The team members wish to recognize their family and friends for support, reassurance, and patience provided throughout the development of the research and this graduate program. The completion of this research process represents the completion of nurse practitioner school and the beginning of a new career. We are beyond grateful for the support that has been provided by our family and friends. Thank you for the many sacrifices that were made so we could follow our dreams. We are forever grateful and will always strive to use the knowledge gained to show God's grace and true care to our patients.

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Evelyn Michelle Rainey

## **Abstract**

In the United States, there are more than 113,000 people on the national transplant waiting list (Health Resources & Services Administration [HRSA], 2019b). The number of people on the waiting list is much larger than the number of donors or transplants. Misinformation or lack of organ donation education results in a decreased number of registered organ donors. A systematic review of the literature identified gaps in the knowledge base regarding organ donation education in the primary healthcare setting. Healthcare providers are trusted sources of information for patients and families and must provide education on the sensitive topic of organ donation. The purpose of this study was to determine if adult patients in the community setting lack basic knowledge regarding organ donation, how knowledge is received, and if there are identifiable factors that affect beliefs regarding organ donation. Ajzen's Theory of Planned Behavior Model was selected to form the theoretical foundation for the purpose of the study. The theory is intended to explain all human behaviors over which people may have the ability to exert self-control, such as the decision to become a registered organ donor or the decision to not become a registered organ donor (LaMorte, 2019).

The researchers initially planned to administer surveys within four primary care clinics in Mississippi during the clinic check in process. Due to the Coronavirus pandemic leading to more telemedicine visits rather than in-person clinic visits, the method of data collection changed. The researchers conducted a quantitative study utilizing a self-developed 18 item questionnaire. The questionnaire inquired about demographic information, knowledge related to organ donation, how organ donation knowledge is received, current organ donor status, and influences that may have contributed to beliefs regarding organ donation. The questionnaire was distributed online through the researchers' personal social media sites using a Google Forms survey and was

accessible via a web-link for patients 18 years and older to anonymously complete. The goal of 400 respondents was achieved. Eighty-six percent of respondents were aged 25 to 60 years old. Most respondents were Caucasian females and highly educated, which also serves as a limitation of the study due to the lack of generalizability of results.

Descriptive statistics, correlational analysis, and selected reliability measures were used to determine answers to the research questions. The results conclude approximately 34% of respondents scored less than 80% on the knowledge quiz, meaning there is a lack of knowledge regarding organ donation in the community setting. Approximately 86% of respondents are already registered organ donors. A statistically significant correlation was found to exist between higher performance on the knowledge portion of the quiz and currently being registered as an organ donor. This study suggests the more educated a person is on organ donation, the more likely the individual is to be a registered organ donor.

The majority of participants did feel like routine organ donation education by a healthcare provider could be beneficial. The study is useful in terms of education for the primary healthcare setting. Healthcare providers could use the results from the study to develop ways to obtain and provide needed education. Optimistically, with proper education, there will be more registered organ donors and additional available organs for transplantation.

## TABLE OF CONTENTS

COPYRIGHT PAGE .....	iii
ACKNOWLEDGEMENTS .....	iv
DEDICATION PAGE .....	v
ABSTRACT .....	vii
TABLE OF CONTENTS .....	ix
LIST OF TABLES .....	xii
LISTS OF FIGURES .....	xiii
CHAPTER I: Dimensions of Problem .....	1
Statement of Problem .....	2
Statement of Purpose .....	2
Significance of Study .....	3
Theoretical Framework .....	4
Research Questions .....	5
Definitions of Terms .....	5
Knowledge Deficit .....	6
Adult Patients .....	6
Registered Organ Donor .....	6

Organ Donation .....	6
Identifiable Factors .....	7
Beliefs .....	7
Assumptions .....	7
Summary .....	8
CHAPTER II: Literature Review .....	9
Summary .....	31
CHAPTER III: Methodology .....	32
Research Design .....	32
Setting .....	33
Population and Sample .....	33
Methods of Data Collection.....	33
Methods of Data Analysis .....	34
CHAPTER IV: Research Findings .....	36
Profile of Study Population .....	36
Statistical Results .....	37
Data Analysis .....	38
Knowledge Deficit.....	38

How Knowledge is Received .....	41
Influences on Beliefs.....	41
Summary of the Findings .....	42
CHAPTER V: Summary and Conclusion .....	44
Summary of the Findings .....	46
Discussion of the Findings .....	47
Conclusions .....	48
Limitations .....	49
Implications .....	50
Recommendations .....	51
REFERENCES.....	52
APPENDICES	
Appendix A: Organ Donation Research Questionnaire .....	56
Appendix B: International Review Board Letter .....	59
Appendix C: Organ Donation Research Questionnaire- MSN Research Project Opening Message.....	60

## LIST OF TABLES

Table 1: Demographics of Survey Respondents (N=400) .....	37
Table 2: Percentage of Knowledge Questions Answered Correctly .....	40
Table 3: Registered Organ Donor Status (N=400) .....	41

## LIST OF FIGURES

Figure 1: Performance on the Knowledge Questions .....	39
Figure 2: Percentage of Where Adults Learn About Organ Donation .....	40
Figure 3: Opportunity for Adult providers regarding organ donation.....	41

## **CHAPTER I**

### **Dimension of Problem**

End stage organ failure is a life changing diagnosis affecting millions of people all over the world. As of July 2019, approximately 250 transplant centers within the United States had more than 113,000 men, women, and children on the national transplant waiting list in hopes of providing the candidates with a lifesaving organ transplant (Health Resources & Services Administration [HRSA], 2019b). Nearly 2,000 transplant candidates are pediatric patients whose ages range from newborn to 17 years old (Health Resources & Services Administration [HRSA], 2019a). Many diseases are congenital or hereditary, but some develop throughout a person's lifespan, leading to organ damage and subsequent organ failure.

Approximately 95% of adults in the United States support organ donation, yet only 58% are actually registered organ donors (HRSA, 2019b). The Health Resources and Services Administration (2019b) reports one person is added to the national transplant waiting list every 10 minutes, and 20 people die every day while waiting for a lifesaving transplant. Only three in 1,000 people die in a way that allows the individual to become an organ donor, thus making the number of patients needing a transplant far outweigh the number of organs available. There is a vital need for adults to receive proper education regarding organ donation, so individuals can make educated decisions regarding registration status. Through solid organ transplantation, one organ donor can potentially save up to eight lives (HRSA, 2019b). Organ donors can become tissue donors as well. One tissue donor could heal up to 75 people in need (United Network for Organ Sharing [UNOS], 2019). Patients who wish to become organ donors may need encouragement or direction in order to complete the registration process and may look to a primary care provider for education and guidance.

Within communities, healthcare providers are trusted to provide adequate education, treatment, and compassion to patients, families, and the general public. The priority for primary care providers is to preserve and optimize health and wellness, which also means to prevent unnecessary pain and death. Adult patients should be informed about what organ donation entails. Inaccurate information related to organ donation and transplantation can negatively influence a person's decision regarding organ donor status. Primary care providers can bridge the gap between fact and fiction by providing factual information and by being available for potential questions regarding organ donation.

### **Statement of Problem**

Many people may not understand the importance of organ donation until directly affected by organ failure within the family, personally, or when approached by an organ procurement team in the event of a family member's imminent death (Michigan Medicine, 2018).

Unfortunately, misinformation, or an overall lack of organ donation education in communities, may result in fewer registered organ donors, leading to a greater number of lives lost through organ failure. Patients are not generally provided with basic education regarding organ donation at any point in adulthood by primary care providers (Degenholtz et al., 2019). Inaccurate information can be spread between family and community members and negatively affect organ donation support and donor registration rates.

### **Statement of Purpose**

The purpose of this study was to determine if adult patients in the community setting lack basic knowledge regarding organ donation, how knowledge is received, and if there are identifiable factors that affect beliefs regarding organ donation. The findings of this study helped determine to what degree of organ donation knowledge deficit was present in adult patients, and

revealed the degree of need for proper organ donation education, which could encourage adults to develop sound beliefs based on information received from a trusted and educated individual.

### **Significance of Study**

If a knowledge deficit is present about any given subject where a decision is to be made, the need for education on the topic is necessary for the individual to make an informed decision. This study is significant to research because the study evaluates and highlights an important need regarding knowledge of organ donation. Research regarding organ donation knowledge deficits has helped to identify patterns and commonalities among surveyed patients within other studies. An identified knowledge deficit revealed where future educational outreach programs could positively impact thousands of patients who are facing, or will face, the need of an organ transplant. This study's significance will further allow for the development of new tools and more focused research goals for future researchers.

For family nurse practitioners and other healthcare team members, this study has been useful in determining the current knowledge base regarding organ donation of adult patients in the United States. The study is useful because the study provides more specific data regarding the adult population and can empower the healthcare provider to attain more education. Taking the data collected into consideration, healthcare providers can implement patient teaching regarding organ donation into each patient's plan of care as needed to improve health and wellbeing for communities.

This study is significant to education because targeted educational interventions may be developed by specialists or professionals to meet the goal of awareness and optimistic change. As an adult patient receives factual education regarding organ donation by a trusted care provider, the adult patient can make an informed decision about whether the individual should

join the national donor registry. The newly educated adult patient can also share the reliable information learned with family or friends.

### **Theoretical Framework**

This research project is supported by Ajzen's Theory of Planned Behavior (TPB), which was proposed by Ajzen in 1985. The theory was developed as an extension of the Theory of Reasoned Action, which was proposed by Fishbein and Ajzen in 1980, and Self-Efficacy Theory, which was proposed by Bandura in 1977 (Ajzen, 1985). The theory is intended to explain all human behaviors over which people may have the ability to exert self-control (LaMorte, 2019). The theory is applicable to the current study because any adult patient can register as an organ donor or not register using the individual's own autonomy.

The TPB links beliefs and behaviors (LaMorte, 2019). The theory states attitude toward behavior, subjective norms, and perceived behavioral control collectively shape an individual's behavioral intentions and behaviors. According to the theory, individuals make logical, reasoned decisions to engage in specific behaviors by evaluating the information available. The performance of a behavior is determined by the individual's intention to engage in the behavior, influenced by the value the individual places on the behavior, ease with which the behavior can be performed, views of significant others, and perception the behavior is within the individual's control. The more favorable the attitude toward behavior and the subjective norm, and the greater the perceived behavioral control, the stronger the person's intention to perform the behavior will be (Ajzen, 2002). In previous studies, the TPB has been successfully used to predict and explain a wide range of health behaviors and intentions including smoking, drinking, health services utilization, breastfeeding, and substance use, among others (LaMorte, 2019).

In the current study, the theory helped explain factors that influence an individual's choice to become or not to become a registered organ donor. Research data was collected in the form of an anonymous questionnaire that was disseminated via Facebook and LinkedIn social media websites. The Organ Donation Research Questionnaire (See Appendix A) helped determine the adult patient's knowledge of organ donation, how knowledge is received, and what factors may influence beliefs or decision to register as an organ donor. With the adult patient's lack of basic knowledge regarding organ donation, the theory can be applied in primary care offices. With this study's data, providers should be able to design educational programs that could influence positive attitudes regarding organ donation and perceived behavioral control among adult patients. Educational programs are needed because proper education may positively influence a person's intentions, which could translate into increased organ donor registration rates. An increase in the number of organ donor registrations increases the possibility someone in end-organ failure may receive a lifesaving organ transplant.

### **Research Questions**

The current research study was based on the following questions:

1. Is there a knowledge deficit among adult patients that could affect the decision to become a registered organ donor?
2. How do adult patients receive knowledge regarding organ donation?
3. Are there identifiable factors that influence an adult patient's beliefs regarding organ donation?

### **Definition of Terms**

For the purpose of this study, the subsequent terms were defined with theoretical and operational definitions, respectively.

### ***Knowledge Deficit***

**Theoretical.** An absence of cognitive information or psychomotor ability required for health restoration, preservation or promotion of health (Wayne, 2016).

**Operational.** Having a knowledge deficit about organ donation would constitute a score of less than 80% on section B of the Organ Donation Research Questionnaire, which addresses ten common misconceptions or myths.

### ***Adult Patients***

**Theoretical.** An individual who has arrived at full development or maturity especially in size, strength, or intellectual capacity (Merriam-Webster, 2019).

**Operational.** Any person who is 18 years of age or older and completed the Organ Donation Research Questionnaire.

### ***Registered Organ Donor***

**Theoretical.** A person who has chosen to become an organ donor and gives legal consent for an anatomical body part to be removed from the body and placed into another person's body (Cleveland Clinic, 2016.).

**Operational.** An adult patient, who at the time of death, has given legal consent, or the family has given legal consent, to donate organs for transplantation by signing up at the Department of Motor Vehicles (DMV), by means of mail in brochures, or via the internet through any given state's online registry.

### ***Organ Donation***

**Theoretical.** The process of giving a deceased person's organs, or part of a deceased person's organ, to another person for transplantation (Donate Life America, n.d.).

**Operational.** The act of a hospital's transplant team retrieving organs from an organ donor after gaining legal consent in order to give the organs to a person in end-stage organ failure who needs a transplant to sustain life.

### ***Identifiable Factors***

**Theoretical.** Elements that contribute to a situation or result (Dictionary.com, n.d.)

**Operational.** Commonalities identified among adult patients through data collected from the Organ Donation Research Questionnaire via section A questions one through four, which address demographic information, and section C questions one, two, and four, which address current organ donor registration status, source of organ donation knowledge, and influence of beliefs that may influence whether or not to support organ donation

### ***Beliefs***

**Theoretical.** The viewing of concepts, people, events, or things to be true despite facts or lack thereof (Business Directory, n.d.).

**Operational.** Acceptance of information about organ donation as fact that is or is not adequately substantiated that was received through a healthcare provider, family member, community event, social media, television show, movie, or possibly an unknown resource.

### **Assumptions**

The researchers developed three assumptions about the study and are listed as followed:

1. Adults who respond to the research questionnaire are willing participants.
2. Participants will be able to read and understand each research question.
3. Participants will select their answers honestly and without outside influence.

## **Summary**

Organ donation saves lives, but there is a disconnect between the need for registered donors and the actual percentage of people who complete the process to become a registered organ donor. Each year, the number of people on the waiting list continues to be much larger than both the number of donors and available transplants. A lack of organ donation knowledge could impede a potential organ donor's decision to become a registered organ donor, which in turn, leads to a greater number of lives lost (Radunz et al., 2015).

Primary care providers are trusted in communities to provide patients of all ages accurate information and education. When an adult patient is educated on organ donation by a primary care provider with an established rapport, the adult patient can make an informed decision about whether to join the national donor registry as a registered organ donor. The findings of this study helped determine the degree of the current knowledge deficit regarding organ donation among adult patients. Findings also helped identify correlating demographical data and identifiable influencing factors which draw attention to the need for proper organ donation education between primary healthcare providers and adult patients on a more routine basis.

## **CHAPTER II**

### **Literature Review**

A comprehensive review of literature pertinent to the current research is presented in this chapter. The purpose of the research was to determine whether adult patients lack basic knowledge regarding organ donation, from where individuals received information regarding organ transplantation, and if there were any identifiable factors that influenced beliefs. The findings of this study helped determine there is a need for proper organ donation education by primary healthcare providers. The purpose of the review of literature is to provide a detailed background explaining how previous studies have influenced the current research.

Sellers et al. (2018) conducted a survey with the purpose of determining if dispelling knowledge deficits and misperceptions associated with organ donation and transplantation would increase donations and decrease waitlist mortality. The researchers wanted to determine the association between an individual's knowledge about organ donation and transplantation, willingness to be an organ donor themselves, and willingness to donate a deceased family member's organs. The primary question was to determine an individual's willingness for personal organs to be donated at death. A second question was to determine a person's willingness to donate a deceased family members organs using three different scenarios: (1) if there had been no discussion with the family member about organ donation, (2) if there had been a discussion with the family member and the family member would like organs donated, and (3) if there had been a discussion with the family member who would not like their organs donated.

While organ transplants have become increasingly successful, the number of patients on transplant waiting lists far exceed the number of organs donated. As a result, many patients wait years for a transplant, which puts patients at increased risk of dying while on the waiting list and

having an increased risk of post-transplant complications and mortality (Sellers et al., 2018). One donor can provide organs for up to nine recipients; therefore, missing one potential donor can be detrimental to many. A major factor limiting organs donated is lack of consent for organ donation, which is affected by knowledge deficits and myths surrounding organ donation. A concern was the patient would not receive as much care by medical staff if the patient was an organ donor. This concern was shown to be the strongest deterrent to organ donation; however, by favorably modifying knowledge deficiencies and myths, donation rates, waitlist survival, and post-transplant outcomes could all be improved (Sellers et al., 2018).

The research by Sellers et al. (2018) was conducted in 2013 using a survey that contained seven questions pertaining to organ donation and transplantation and willingness to donate organs. Following analysis, results showed 648, or 84.6%, of respondents were willing to donate personal organs (Sellers et al., 2018). The willingness of respondents to donate family members' organs varied depending on whether the respondent discussed organ donation with the family member. If no discussion was had, 61% of respondents were willing to donate family members' organs. If there had been a conversation and the family member would like organs donated, 95.2% of respondents were willing to donate family members' organs. If there had been a conversation and the family member would not like organs donated, only 11% of respondents were willing to donate family members' organs. Concern about receiving inadequate care from medical personnel if registered as an organ donor was present in 11.8% of respondents. Just over half, 53.3%, of respondents with this concern were willing to donate, while 88.9% of respondents without this concern expressed willingness to donate. Concern regarding inadequate care was the strongest predictor of willingness to donate, and African Americans were more likely than Caucasians to have the concern (Sellers et al., 2018).

Respondents who believed a patient could recover from brain death were 21.8% (Sellers et al., 2018). Nearly 88% of respondents knew brain death was not recoverable and were willing to donate organs. The majority of respondents, 78.3%, understood the main problem regarding organ donation is shortage of organs, and this factor was associated with willingness to donate. When considering donation of family members' organs, another drawback was the belief that donating a family members' organs would increase personal costs (Sellers et al., 2018).

These results from the study by Sellers et al. (2018) imply myths and misperceptions do affect a person's willingness to donate organs. Concern regarding receiving inadequate care from medical personnel if registered as an organ donor was most predictive of willingness to donate (Sellers et al., 2018). Public outreach with the purpose of eliminating misperceptions would be beneficial.

The study by Sellers et al. (2018) is relevant to the current research because the purpose was also to determine if dispelling knowledge deficits and misperceptions associated with organ donation and transplantation would increase donations and decrease waitlist mortality. The current researchers determined a patient's lack of knowledge about organ donation affects willingness to become an organ donor. The researchers also attempted to determine where the patient received false or misleading information. The main goal of the Sellers et al. (2018) study and the current research is to educate the public and increase organ donation.

Siminoff and Arnold (1999) conducted a study to determine factors in the African American community that contribute to the lack of organ donation, specifically those who reside in the deep south. African Americans are overrepresented on the waitlist to receive vital organ transplants in America, yet they are underrepresented in the organ donation category. Siminoff and Arnold (1999) attempted to answer the question of why the African American community is

so hesitant to donate their organs. By answering this question, the research team believed that more focused, community-based intervention campaigns could be put into place to increase donor registration.

Siminoff and Arnold (1999) conducted a study in Alabama where participants were African American, at least 19 years old or older, and lived in both rural and urban areas. Advertisements regarding organ donation were dispersed through networking channels that included a phone number interested parties could call for further information (Siminoff & Arnold, 1999). Six focus groups ranging in size from eight to 19 participants were brought together and included both registered and unregistered organ donors. Three paths to becoming an organ donor were supplied to participants, including Department of Motor Vehicle registry, mail in brochures, and online registration. The participants were asked targeted questions about behavioral beliefs, subjective norms, and behavioral control. The final survey instrument was a compilation of 13 organ donor attitude questions, 14 organ donor awareness questions, and six questions about general knowledge of organ donation. Participants were also asked about the advantages or disadvantages of becoming a registered organ donor, if others would approve or disapprove of becoming an organ donor, and what circumstances would enable or hinder becoming a registered organ donor (Siminoff & Arnold, 1999).

The opportunity to save a life accounted for 51.6% of the answers to the question regarding advantages of becoming an organ donor (Siminoff & Arnold, 1999). The ability to decide whether or not a person wanted organs donated and leaving the decision to family members was second with 20%, and another 8.3% cited the lack of need for organs after death. The lack of need for organs after death emerged frequently in focus groups, with many agreeable to the point as an advantage of organ donation. When discussing disadvantages, the biggest

hindrance was fear. Legal and moral issues and organ viability were also raised as possible concerns. Family members were also cited as being the most likely to disagree with organ donation, accounting for 51% of answers. The most common barrier to becoming an organ donor was lack of education and information, accounting for 40% of responses (Siminoff & Arnold, 1999).

The study by Siminoff and Arnold (1999) relates to the current researchers' study in that Siminoff and Arnold successfully measured factors that would encourage and restrict organ donation in African American communities. The overall findings suggest revised messages and content should be developed and distributed in effort to increase organ donation in the target audience (Siminoff & Arnold, 1999). One question the current researchers asked was where participants' knowledge regarding organ donation was obtained. The study by Siminoff and Arnold (1999) supported a need for organ donation education in the African American population.

Thornton et al. (2016) performed a randomized controlled trial with the purpose of determining effects of an informational video intervention for patients and a cueing question for primary care providers on the number of patients who discussed organ donation with the provider and the number of patients who agreed to register as an organ donor. The study was conducted at 18 primary care clinics of the MetroHealth System located in northeastern Ohio (Thornton et al., 2016). Patients had to be English speaking, over the age of 15.5 years, had not previously consented to organ donation, and had a scheduled appointment with a provider at a participating clinic planned in the upcoming week in order to participate in the study. Regular providers were primary care physicians or nurse practitioners who had seen the patient for at least two health maintenance visits in the last three years. Participants were screened from

February 2013 until the target sample was reached in May 2014. Of the 8,264 patients who were screened, 915 were enrolled in the study and were divided into computer-generated randomized intervention and control groups. Three months prior to starting the study, the primary care providers received information about the study, an instructional pamphlet about organ donation, and a list of frequently asked questions and answers regarding organ donation (Thornton et al., 2016).

On the day of patients' appointments, participants arrived 45 minutes prior to the appointment (Thornton et al., 2016). The study was then described to participants in more detail, and patient willingness and eligibility to participate were finalized. Patients had already been presorted into intervention and control groups. Participants in the intervention group watched a five minute, professionally produced video on organ donation that had already been shown to be effective in increasing organ donation consent. Participants chose one of 12 possible questions regarding barriers to organ donation or wrote a question. Questions were printed out and given to the patient to discuss with the provider. The control group would meet with the primary provider as usual after consenting to participate in the study. Both groups were interviewed following the appointments. Participants were asked if the participant had discussed organ donation or advanced directives with the provider and if the participant was satisfied with the answers provided and time spent with providers. Finally, participants were asked if the participants would like to consent to organ donation, and the study staff verified that patients provided valid consent. Participants were given \$20 for participation (Thornton et al., 2016).

The intervention patient group was more likely than the control group to consent to organ donation (Thornton et al., 2016). Intervention group participants were also more likely to sign up soon to donate organs than the control group. The researchers did not find a difference between

groups regarding patients who expressed willingness to donate a kidney while living. The intervention group was much more likely than the control group to have discussions with the provider about organ donation. Of the visits that did include an organ donation discussion, patients were more likely to start the conversation than the provider. The intervention patients were also more likely to discuss living wills and advanced directives along with organ donation. A brief informational video on organ donation and patient cueing was successful in increasing organ donation discussions between patients and primary care providers, which leads to increased patient consent for organ donation. The primary care setting may be an appropriate area to advocate for organ donation along with conversations about living wills and advanced directives. Many patients have a distrust of the healthcare system and have a lack of knowledge about organ donation. Primary care providers could use the established relationship with patients to provide information and address any concerns. Additionally, patient preferences to be documented in the medical record (Thornton et al., 2016).

The study by Thornton et al. (2016) is relevant to the current research because the basis of the study seeks to improve organ donation by providing educational information about organ donation and cueing questions for the patient to ask the primary care provider. The study noted providing information in the primary care setting led to increased discussions and consent for organ donation (Thornton et al., 2016). The research is similar in that the current researchers also attempted to determine if patients' lack of knowledge about organ donation affects willingness to become an organ donor. The current research study helped determine that routine organ donation education is appropriate in the primary care setting.

Philpot et al. (2016) performed a qualitative, randomized, double blind, controlled trial where members of the community viewed one of two videos of a simulated organ donation

conversation that differed only in the amount of information provided about organ donation benefits. The study showed that families are more likely to say “yes” to donation if the conversation includes information about the rarity of the ability to donate and if the requestor has a positive attitude regarding organ donation (Philpot et al., 2016). The study was designed to compare the attitude of participants after viewing the simulated “supportive” versus “control” videos. Participants who viewed the “supportive” donation conversation video, where information was provided regarding the benefits of donation, would feel the family had been adequately informed to make a choice about organ donation (Philpot et al., 2016).

In an electronic newsletter, a request was sent to over 30,000 staff members of a large, Australian organization requesting participation in the study (Philpot et al., 2016). Participants were asked to answer questions regarding demographics, personal experience with organ transplantation or organ donation, and personal attitudes toward donation. Participants read a short scenario and were then randomly chosen to watch a video of a pre-recorded conversation between a doctor and a family member about organ donation. The “supportive” video differed from the “control” video only in that the “supportive” video provided information about potential benefits of donation and transplantation, the rarity of the opportunity to be a donor, and need for donated organs. After completion of the video, participants were asked to reflect on the video and assess the level of agreement with four statements. The statements were anonymously assessed by participants using a Likart scale and were submitted electronically at the time of survey completion (Philpot et al., 2016).

There were 665 people who followed the link and entered demographic data, but not all finished the survey (Philpot et al., 2016). Six hundred twenty-eight participants finished the survey and entered baseline information about opinions and experiences with transplantation and

organ donation, and 474 participants completed the survey and watched one of the two videos. The “supportive” video was viewed by 235 participants, and the “control” video was viewed by 239 participants. Younger participants, who were more likely female, began the survey questions but did not finish. Individuals who did not finish were more often in the “other religion” group and more commonly knew someone who had been an organ or tissue donor. Viewers in the “supportive” group were more likely to retain information provided. Regarding influence or persuasion by the doctor, neither group was more likely to report the doctor cared more about potential transplant recipients than about the donor patient and family in the scenario. The groups were equally as likely to report the doctor cared about the patient and was helping the family make a decision that was right for the patient’s family (Philpot et al., 2016).

The researchers concluded community members who watched the “supportive” family donation conversation video obtained a higher level of factual and satisfactory information. Participants were more likely to report the doctor was trying to convince the family members to say yes, but despite this finding, participants did not feel uncomfortable or as if the doctor cared more about the transplant patient than the potential donor and family. The researchers suggested the finding may be influential in a family’s willingness to provide consent for organ donation. Since 81% of participants in the “supportive” group, versus 35% in the “control” group, remembered the act of being an organ donor is a rarity, the researchers concluded the “supportive” group was influenced by receiving the positive information during the video (Philpot et al., 2016).

The study supported the hypothesis that providing information about the rarity of having a donation opportunity and overall benefits of having a family conversation as positive (Philpot et al., 2016). Individuals can provide information about the process of organ donation without

fear of coercing families into giving consent against the patient's wishes, further supporting that participants who viewed the "supportive" videos felt adequately informed to make a decision about organ donation (Philpot et al., 2016).

The study by Philpot et al. (2016) is relevant to the current research study. The topic of organ donation is not often brought up until patients are at a critical time. Although the study was conducted in Australia, the basics of the conversation are comparable. Both studies demonstrate primary care providers need to educate patients and family members regarding organ donation so educational opportunities are provided prior to a critical time that may be influenced by grief and stress (Philpot et al., 2016).

Natt et al. (2017) performed a quantitative study in a clinic with the purpose of increasing registered organ donors by 10%. The researchers hypothesized attaching a donor registration form to a donor informational pamphlet would minimize delayed registrants, as the other ways to register were via online registration links or in person through a government agency (Natt et al., 2017). The researchers speculated a paper registration form would be more efficient because the paper form would serve as a tangible visual aide. Natt et al. (2017) also hypothesized some clinic physicians may have concerns a patient's primary purpose for the visit may not be addressed if more time is spent answering questions about organ donation, there is not adequate staffing to disperse or take up forms, or the providers are not properly educated on organ donation and may not be able to appropriately answer patients' questions.

This study highlighted the lack of opportunity potential organ donors had to converse with specialized healthcare providers regarding any concerns or questions related to organ donation (Natt et al., 2017). In Canadian hospitals, the duty of approaching the family of a potential organ donor often falls to the intensive care unit physician, which may or may not

occur depending on the physician's time, comfort level, and level of training on organ donation. After reviewing studies where kiosks and informational videos shown in primary clinics showed improvement in donor registration rates, Natt et al. (2017) proposed a quality improvement initiative that involved providing patients with an educational pamphlet containing key facts about an organ donation and organ donor registration form. The patients were given time to view the material in the clinic waiting room while patients waited to be called back for appointments (Natt et al., 2017).

Natt et al. (2017) conducted three Plan-Do-Study Act (PDSA) cycles for the study. Patients were asked if the patients were registered donors, which allowed the patient to serve as a control and a comparison tool to show the interventions posed would influence people who were not registered organ donors to register (Natt et al., 2017). The first PDSA cycle was a pilot test to determine the clarity of the pamphlet created, which highlighted key aspects of the organ donation process, common myths, and the importance and need for organ donors. The pamphlet also provided resource information. and was dispersed to a convenience sample of nine patients at the clinic who were asked to rank the clarity of the pamphlet, whether emotional discomfort was felt when reviewing the pamphlet, and if the information provided would persuade the reader to register as an organ donor if not already registered. Baseline data from the 60 patients was used in the second and third PDSA cycles. The second PDSA cycle included disbursement of a revised pamphlet and a paper registration form that served as a readily accessible, convenient option for the patient to use to register as an organ donor while at the clinic. The registration forms were reviewed to ensure completion and were mailed to the area's organ procurement organization. The patients and clinical staff reported positive feedback on the ease of receiving, distributing, and collecting the information. The third PDSA cycle used a graphic

to replace a statistical fact sheet and was collected in the same manner as previous PDSA cycles. The interventions resulted in an 18.3% increase of registered organ donors in one primary care clinic, which surpassed the initial 10% goal. (Natt et al., 2017)

The study by Natt et al. (2017) is relevant to the current research because the study displays evidence that even the slightest intervention of providing educational information to patients may increase the organ donor registration rate. The United States uses a similar organ donation registration system in that a person can register online, at a specific government agency, or by mailing in paper registration forms. The data provided by Natt et al. (2017) shows there are barriers to cross when approaching the topic of organ donation education in a primary healthcare setting, and there is a lack of literature available regarding organ donation registration efforts or organ donation education provided in the primary healthcare setting. Primary care providers should be educating patients regarding organ donation in the primary health care setting.

Merola et al. (2016) performed a cross-sectional survey for the purpose of assessing donor registration rates, perceived barriers to donation, and attitudes toward organ allocation among patients on the transplant waitlist. The researchers believed a lack of education by healthcare professionals could be contributing to the development of misconceptions regarding organ donation (Merola et al., 2016). The purpose of the study was to gather statistics on current waitlisted patients to determine current donor registration status, knowledge regarding organ donation, barriers to donor registration, and attitudes of organ allocation and reciprocity. The researchers also wanted to determine if physicians were discussing organ donor designation with end-stage organ failure patients. Merola et al. (2016) conducted a cross-sectional study over a six-month timeframe. The study was performed among patients who were active on the transplant waitlist at Yale-New Haven Hospital, an academic tertiary care hospital in

Connecticut. There were 579 patients on the waitlist at the time of survey distribution. The research team developed a questionnaire to collect information from patients regarding demographics, current donor registration status, knowledge and barriers regarding organ donation, and attitudes regarding the allocation process and reciprocity. The non-demographic information was evaluated using a five-point Likert scale (Merola et al., 2016).

Merola et al. (2016) divided the five-point Likert scale into a three-component scale of agree (4 and 5), not sure (3), and disagree (1 and 2) due to having a small sample size. Respondents were categorized as unwilling to donate as “unwilling”, and those that were already registered donors as “registered.” Another category was designated as “uncommitted,” for participants who were interested in donation but not registered, unaware how to register, and were considering donation but were unsure at the time of the survey. The collected data was compared between the three groups using Analysis of Variance (ANOVA). Researchers further compared results by using multivariate multinomial logistic regression models. The majority of the respondents were male (58%), Caucasian (67%), of Christian faith (76%), married (58%), parents (70%), reported knowing an organ transplant recipient (59%), and held a driver’s license (94%). The mean age of participants was 55.7 years old. Nearly half the participating patients affirmed barriers and misconceptions surrounding organ donor designation among end-organ failure patients. Participants lacked knowledge regarding organ donation. Thirty-four (31%) patients recalled having a discussion regarding donation with transplant providers (Merola et al., 2016).

Attitudes of the current organ allocation system and reciprocity had varied results (Merola et al., 2016). Forty-four percent felt the current system is fair, 18% felt patients who are registered donors should be given priority, 48% felt organs should be prioritized based on

severity of patient illness, and 33% felt patients with the longest post-transplant life expectancy should be given priority. Seventy-one respondents reported being registered organ donors, while 64 respondents did not plan on becoming an organ donor. The study found non-native, English-speaking, and male patients were less likely to be committed to organ donation. Patients who reported knowing an organ donor, beliefs regarding eligibility for donation, health status, and prior discussion of organ donation with transplant providers showed significant correlation with donor registration status. Patients who were already registered for donation were 3.5-fold more likely to have discussed donation with a transplant provider than patients in the “uncommitted” category (Merola et al., 2016).

Patients who had not had a discussion with a transplant provider reported more barriers and misconceptions (Merola et al., 2016). The researchers stressed the importance that providers educate patients on organ donation registration, eligibility, and common misconceptions to help improve donation registration rates among waitlisted patients. The current allocation system does not exclude end-organ failure patients from donor registration. Furthermore, if current waitlisted patients join the donor pool, there would be a significant increase in organ donor registrants leading to additional transplants occurring. The research team stressed the implications for implementation of provider-based education programs to help increase patient knowledge regarding organ donor eligibility and decrease barriers among waitlisted patients (Merola et al., 2016).

Loughery et al. (2018) conducted a cross-sectional study to help understand attitudes of individuals with stage five chronic kidney disease (CKD) toward being a deceased organ donor through development of a validated tool to assess beliefs. The researchers wanted to understand the use and implications of the developed tool in increasing awareness of deceased organ

donation among individuals on dialysis (Loughery et al., 2018). Previous research has been done to view attitudes of people with CKD toward receiving a living kidney donor transplant, but no research has been conducted on patients' attitudes toward being deceased organ and tissue donors. Misconceptions regarding organ donation are a major barrier to increasing the donor registration rate. The researchers hypothesized people with chronic health conditions, such as stage five CKD, may believe the individuals are unable to donate organs after death. An additional purpose of the study sought to examine the psychometric properties of a new organ donation scale adapted from a previous survey instrument created by the researchers. The new scale addressed organ donation barriers, benefits specific to dialysis patients, and common barriers and benefits to donation (Loughery et al., 2018).

Data was collected from 554 patients with stage five CKD at 12 dialysis units in southeast Michigan (Loughery et al., 2018). The study took place from June 2011 to September 2013. Patients who were on in-center hemodialysis, home hemodialysis, or peritoneal dialysis were included. Patients were excluded from the study if the patients were younger than 18 years of age, non-English speaking, less than 90 days on dialysis, unable to provide consent due to dementia or cognitive impairment, or had a red heart sticker on the driver's license, indicating enrollment in the Michigan Organ Donor Registry (DR). The research group revised a survey previously used in organ donation studies to make the survey more specific to dialysis patients. The researchers added five items to address dialysis specific barriers and benefits. Baseline measurements included attitudes toward organ donation, enrollment status on the donor registry, intention to donate, awareness of the donor registry, personal connections to organ donation, and demographics (Loughery et al., 2018).

A total of 1,294 patients were approached to participate in the study (Loughery et al., 2018). There were 554 patients, 314 in the intervention group and 239 in the control group, who consented and completed the survey. Half the sample were older than 60 years, more than half were male, 74% were African American, and half reported an annual income below \$20,000. Regarding personal connection to organ donation, 45% of respondents indicated pursuing an organ transplant. Regarding awareness, 63% had heard of the donor registry. Patients who were older than 60 years, white, or of higher education status reported more positive attitudes. On dialysis-specific survey items, 29% responded neutral to “strongly agree” to the statement, “Dialysis patients cannot donate any organs at all.” Comparably, 27% answered neutral to “strongly agree” to the statement, “Dialysis patients are too sick to donate their organs,” and 39% responded neutral to “strongly agree” to, “I would donate my organs, but they would not accept my organs.” The researchers’ hypothesis proved to be true. Misconceptions among stage five CKD patients are common, and there is a need for education. Although the individuals cannot donate kidneys, the patients may be able to donate other organs and tissues (Loughery et al., 2018).

Loughery et al. (2018) identified two subscales with good psychometric properties as general benefits ( $\alpha=0.86$ ) and general barriers ( $\alpha=0.80$ ). On both scales, more positive donation attitudes were associated with higher intent to sign up as an organ donor (Loughery et al., 2018). The findings in the study could be shared with healthcare professionals and administrators at dialysis units to dispel the myth the topic of organ donation is too sensitive to be discussed with dialysis patients. Study participants were open to discuss deceased organ donation. Implications for further research include that the survey could be administered to patients with any stage of CKD to understand beliefs regarding the ability of a person with CKD to donate organs after

death. The findings can be used to design individualized education that addresses the knowledge deficit and barriers (Loughery et al., 2018).

The research study by Loughery et al. (2018) is relevant to the current study for several reasons. The study identified a reliable and valid survey tool used in prior organ donation studies but revised the tool to be more specific to dialysis patients (Loughery et al., 2018). The research findings identified a knowledge deficit regarding common misconceptions and eligibility of organ donation among stage five CKD patients. Lastly, the researchers suggested further research among individuals with other chronic health conditions and attitudes regarding organ donation. Individuals with chronic health conditions completed the current researchers' survey regarding organ donation (Loughery et al., 2018).

Doherty et al. (2017) conducted a cross-sectional survey with the purpose of determining if including or excluding positive or negative affective attitudinal questions would affect a person's intention to become an organ donor. There continues to be a lack of available organs for transplant. Doherty et al. (2017) believed attitudes about organ donation are important predictors of organ donation registration rates and the balance between positive and negative attitudes should be studied. The researchers focused particularly on affective attitudes toward organ donation that relate to an individual's feelings or emotions, such as fear, misunderstanding about the process of procuring organs, discomfort when talking about death and dying, and disgust toward medical procedures (Doherty et al., 2017). One hypothesis stated omitting negatively worded items on a questionnaire would be associated with an increased intention to become an organ donor, increased rates of organ donor behavior, and accepting an organ donor card. Researchers planned to manipulate the presence of positive or negative affective attitudes to examine the effects on a person's intention to donate or take a donor card (Doherty et al., 2017).

The study by Doherty et al. (2017) was conducted in Ireland using a modified version of the Attitudes to Organ Donation Questionnaire that reflected the status of organ donation in Ireland. Participants included an opportunistic sample of the public, aged 18 and over, who were recruited by four medical students at four large shopping centers in Ireland that serve different demographic and socioeconomic populations (Doherty et al., 2017). Participants provided information regarding age, health insurance, and attitudes toward organ donation and gave verbal consent. No identifying data was obtained from participants. Researchers used a questionnaire that measured multiple items including affective attitudes, perceived benefits, bodily integrity, medical distrust, ick factor, jinx factor, anticipated regret, cognitive attitudes, perceived behavioral control, intention, and subjective norm. At the end of the questionnaire, participants were offered an organ donation card and acceptance was documented (Doherty et al., 2017).

Doherty et al. (2017) confirmed emotional factors do play a role in predicting organ donor status. Higher scores on anticipated regret and subjective norms questions increased the probability of the participant being willing to donate (Doherty et al., 2017). Higher scores on bodily integrity, medical distrust, and the “ick” and jinx factor questions were associated with a decreased probability of the participant being willing to donate. An increased intention to donate was associated with a much higher likelihood of acceptance of a donor card at the end of the questionnaire. The questionnaire that omitted all affective attitudinal items showed a greater intention to donate and a marginally higher rate of acceptance of an organ donor card among non-donors. By omitting emotionally sensitive factors, participants were not prompted to elicit positive or negative feelings and were able to decide to donate based on other components of the questionnaire. The finding shows organ donation may sometimes be perceived as an emotionally difficult subject for people, which could affect willingness to donate organs. By asking questions

that do not elicit an emotional response, future researchers may continue to improve outcomes. The study was able to show a correlation between intention to become an organ donor and organ donor behavior, with similar findings for both factors (Doherty et al., 2017).

The study by Doherty et al. (2017) is relevant to the current research because the study used a questionnaire to determine if the presence of positive or negative affective attitudes would affect an individual's intention to donate or take a donor card. The results confirm emotional factors do play a role in predicting organ donor status (Doherty et al., 2017). The current researchers also used a questionnaire to not determine whether patients lack basic knowledge regarding organ donation and to determine where or from whom the patient may have received information, and what influences beliefs regarding organ donation.

In a study conducted by Katz et al. (2019), a quantitative design study was used to understand the reluctance to register for organ donation. The researchers proposed anxiety of death and the dying process produced a reluctance to become an organ donor (Katz et al., 2019). The study found 85% of participants are supportive and agree with organ donations, but only 40% to 45% are registered organ donors. Common beliefs that influence registration for organ donation are anxiety related to death, integrity of the body after death, and anxiety regarding proper patient care from healthcare providers if registered as a donor. The Theory of Planned Behavior (TPB) was the theoretical framework used for the study. The theory was used to predict behaviors that people may have self-control over. In the Katz et al. (2019) study, the behavior addressed was attitude toward organ donation and the likelihood of action to become a registered organ donor.

The study was conducted online using Qualtrics data collection systems (Katz et al., 2019). A sample set of adults over the age of 21 years received email invitations to participate in

the study without being given any details regarding the contents of the survey. Each participant received a dollar incentive to participate. The sample size was 777 participants; 423 were in the United States, and 354 were in the United Kingdom. The response rate was 11.8%. The sample demographics were gender, family status, children, income level, and education. Four variables were studied. The first variable was the lack of control, which included fear of not receiving necessary medical attention, afraid organs will be removed before death, concerned organs will not go to those who really need them, and worried about how the body will be treated after death. The second variable, need for information, included what happens to a donor's body after harvesting, transplant process, if doctors will make every effort to save the donor's life, and information about how organs are used. The third variable, trust, included how often respondents trust other people, belief that most people can be trusted, and to what extent do participants trust doctors and nurses. The fourth variable, prosocial, included that organ donations help save lives, advance medical research, give recipients a better quality of life, and are the right thing to do. The outcome variable asked participants if the individuals were registered as organ donors and, if not, would participants be willing to register (Katz et al., 2019)?

After collection and statistical analysis of data, results revealed skewness was between negative one and one for 13 of the 17 variables (Katz et al., 2019). The need for information was positively associated with lack of control, and trust was negatively associated with lack of control. The need for information was marginally associated with registration status, and lack of control was negatively associated with registration status. Results also showed registered donors who took part in the survey believe in prosocial behaviors, and prosocial behaviors are positively associated with organ donation registration status. Findings support the theoretical model that individuals who are not registered organ donors are impacted by feelings and behaviors of lack

of control over the body, mistrust, and the need for more information regarding organ donation (Katz et al., 2019).

The study by Katz et al. (2019) correlates with the current research regarding knowledge deficits on organ donation. Katz et al. (2019) focused on factors that influence organ donation registry, which directly correlates with the current study. The current researchers did not intend to test the same tools that were evaluated by Katz et al. (2019), and the research and methodology varied, yet the assessment of indicators that determine organ donation registry were similar. The study by Katz et al. (2019) showed the importance of organ donation and providing ways more people will become registered donors. Results obtained from the current study also suggests further research is needed for more in-depth knowledge regarding organ donation and how to increase the number of organ donors.

Salim et al. (2015) performed an observational study to examine how effective distribution of organ donation education material would be for Hispanic Americans via kiosk machines placed in primary healthcare clinics. In America, minority ethnic populations have a pronounced shortage in relation to organ donation registration rates (Salim et al., 2015). Salim et al. (2015) hypothesized that since focused educational programs carried out within places of worship and at high schools significantly improved the perception, knowledge, and beliefs of Hispanics regarding organ donation, the results should also be significant in other venues, such as primary healthcare clinics. Primary clinics were not used as a resource center for distribution of organ and tissue donation information to the Hispanic population in the past. Since end-stage organ failure affects people of all cultures and backgrounds, the lack of ethnic minority organ donors constitutes a major concern for primary healthcare providers (Salim et al., 2015).

Kiosks containing educational material on organ donation were placed at four healthcare clinics for seven weeks in a California neighborhood that had a high percentage of Hispanic residents (Salim et al., 2015). Three clinics were primary healthcare clinics and one was a hospital-based clinic. For the first three-week period, the kiosks were unstaffed. Then, for one week, the kiosks were staffed by a representative from the local organ procurement center. The project was completed by an additional three-week period with no staff at the kiosks. The kiosks had a descriptive poster containing organ donation education material and blank organ donor registration forms that could be completed by the patient if interested. A box was placed next to the educational poster where donor registration forms could be left. During the week when kiosks were staffed, bilingual representatives engaged with patients. The number of patients seen at the four healthcare clinics and the number of patients who chose to register were documented and analyzed. The primary endpoint was the donation rate per 1,000 client encounters. Using the exact binomial method, the rate for each clinic per time period and the 95% confidence interval was derived. Differences in the overall rate between unstaffed periods and staffed periods were examined using the two-sided Fisher's exact test, and data was analyzed using statistical software (Salim et al., 2015).

In the six weeks kiosks were not staffed, 59,181 patients were encountered (Salim et al., 2015). During that time, two patients completed organ donation registration forms, which produces a rate of 0.03 per 1,000 in one of the four clinics. During the week kiosks were staffed by a member of the organ procurement agency, a total of 9,805 patient encounters were recorded and 102 patients signed up to be a registered organ donor. The registration rate went up to 10 per 1,000 patients. From the three community clinics, 81 patients registered during the staffed week, bringing a registration rate of 12 per 1,000. At the hospital-based clinic, 21 patients registered,

bringing the rate for that one clinic to seven per 1,000 during the staffed kiosk week (Salim et al., 2015).

This study by Salim et al. (2015) is relevant to the current research study. By having the study in healthcare clinics, researchers showed that multiple patients chose to register as organ donors when provided the opportunity, which is aided by having an educated person on hand who can answer questions and concerns. The study shows education on organ donation can lead to an increase in the number of registered organ donors and that primary healthcare clinics could be a good place to start (Salim et al., 2015).

### **Summary**

All previous information gathered to support the basis of the current research project was utilized to form the tool to determine if there is a knowledge deficit among adult patients that affects the decision to become an organ donor, where individuals receive information regarding organ donation, and factors that influence an individual's beliefs regarding organ donation. Literature also revealed a need for further research on the subject matter and an increase in education regarding organ donation, further validating the need for this study

## **CHAPTER III**

### **Design and Methodology**

The act of organ donation occurs when an individual makes the decision to donate an organ, whether from a deceased individual or living person, to a living person who is in need of organ transplantation to sustain life. Organ donation affects the individuals who need the transplant and family and friends of the individual. Adult patients are not generally provided with basic education regarding organ donation by primary care providers (Philpot et al., 2016).

Lack of organ donation education has resulted in a decrease in the number of registered organ donors, which has caused many lives to be lost and an increase in the number of people affected by the loss of loved ones (Thornton et al., 2016). Many people do not understand the importance of organ donation until directly affected by organ failure or when approached by an organ procurement team in the event of a family member's imminent death (Michigan Medicine - University of Michigan, 2018). The purpose of this study was to determine whether adult patients lack basic knowledge regarding organ donation, to evaluate how organ transplant knowledge is received, and if there were any identifiable factors that might influence beliefs regarding organ donation.

#### **Research Design**

After Institutional Review Board (IRB) approval (See Appendix B) was obtained, the researchers conducted a quantitative research study surveying men and women over the age of 18 years regarding knowledge related to organ donation and transplantation. The researchers' original intention was to distribute a pen and paper survey to adult patients at four primary care clinics in Mississippi, but due to the Coronavirus crisis, the planned method was not possible. The researchers developed an online questionnaire as a substitute using the same questions that

would have been on the pen and paper survey. The survey helped determine if adult patients have a knowledge deficit or erroneous beliefs that might affect the decision to become a registered organ donor. The survey was also used to determine how adult patients received knowledge regarding organ donation, if there were factors that influenced beliefs regarding organ donation, and the participant's current status on the organ donor registry.

### **Setting**

The setting for this research study was a web-based questionnaire in the form of Google Forms that was shared using social media platforms, Facebook and LinkedIn. The researchers typed an opening message that was uploaded to personal social media accounts with the link to the survey (See Appendix C). This study included men and women of all races who were 18 years of age or older. The researchers' goal was to survey at least 400 participants, and the number of surveys returned was 400. Once the goal was reached, the questionnaire was deactivated by the researchers.

### **Population and Sample**

This research study was a quantitative study that surveyed men and women who accessed the questionnaire via the Google Forms link uploaded on Facebook and LinkedIn. In order to be considered for the data analysis, respondents were required to be 18 years of age and older and have access to social media.

### **Methods of Data Collection**

The researchers of the current study created a questionnaire, and then used the platform of Google Forms to distribute the survey anonymously. The survey's online link was uploaded onto the researchers' personal Facebook and LinkedIn accounts. The survey was available for

approximately one hour until the number of participants reached 400. Once the study was completed, the researchers retrieved the data from Google Forms for analysis.

The Organ Donation Research Questionnaire included 18 questions. The first four questions captured demographic information. The next 10 questions addressed knowledge and common beliefs related to organ donation. The final four questions addressed current donor status; where participants' current knowledge about organ donation was obtained; whether or not having an opportunity to receive education about organ donation from a healthcare provider would be beneficial; and possible religious, spiritual, or personal beliefs that influence participants to support or not support organ donation in any way. The completed survey results were then reviewed by the researchers for data analysis.

### **Methods of Data Analysis**

Data from the completed surveys was then subjected to analysis using descriptive statistics that included frequency distributions and percentages. Data was analyzed to determine if adult patients had a knowledge deficit that could affect the decision to become a registered organ donor, how adult patients obtained knowledge regarding organ donation, and if there were factors that influenced beliefs regarding organ donation. Using the analysis method of correlation helped the researchers to discover an incidental finding from the study.

### **Summary**

The purpose of this study was to determine whether adult patients lack basic knowledge regarding organ donation, to evaluate how individuals obtain organ donation knowledge, and if there are any identifiable factors that might influence beliefs regarding organ donation. The data was collected via an online survey that was completed by adult patient respondents through Google Forms. Prior research has revealed a knowledge deficit regarding organ donation among

adult individuals and the need for further research and evidenced-based interventions by primary care providers. Researchers have found that providing organ donation education in the primary care setting will lead to increased discussions and consent for organ donation (Thornton et al., 2016). The findings could help primary care providers in the future with implementation of proper organ donation education in the primary care setting.

## **CHAPTER IV**

### **Research Findings**

The purpose of this research study was to determine if adult patients lack basic knowledge regarding organ donation, evaluate how individuals receive organ donation knowledge, and if there were any identifiable factors that might influence beliefs regarding organ donation. There is a vital need for adult patients to receive proper education regarding organ donation, so individuals can make educated decisions regarding personal donor status. Through solid organ transplantation, one organ donor can potentially save up to eight lives; organ donors also have the ability to become tissue donors as well, which has the potential to heal up to 75 people in need (UNOS, 2019). The study is significant to research because the study evaluates and highlights an important need where education could positively impact thousands of patients who are facing, or will face, the need of an organ transplant.

#### **Profile of Study Population**

Data from the current research was obtained by performing a quantitative study that surveyed men and women who accessed a questionnaire via the Google Forms link uploaded to Facebook and LinkedIn. Demographic data included age, gender, race, and highest level of education completed. The researchers also left a space at the end of the questionnaire where participants could leave any comments, feedback, or optional reflections regarding organ donation or the research questionnaire.

The link to the survey was shared onto the researchers' personal social media platforms of Facebook and LinkedIn. The survey was available for approximately one hour until the goal number of participants reached 400, at which point the survey was disabled. Approximately 45% of respondents were in the 40 year to 60-year-old age group, and 41% were in the 25 year to 39-

year-old age group. The sample was overwhelmingly female (93.3%) and Caucasian (96.5%).

The sample is also highly educated, with 65.7% being a college graduate.

**Table 1**

*Demographics of Survey Respondents (N=400)*

	<b>Number of Respondents</b>	<b>% of Respondents</b>
<b>Gender</b>		
Female	373	93.3
Male	27	6.8
<b>Age</b>		
18-24 years	15	3.8
25-39 years	164	41.0
40-60 years	179	44.8
60+ years	42	10.5
<b>Race</b>		
African American	4	1.0
Asian	2	0.5
Caucasian	386	96.5
Hispanic	5	1.3
Multi-racial	1	0.3
Other	2	0.5
<b>Education Level</b>		
Less than High School Graduate	2	0.5
High School Graduate or GED	27	6.8
Some College	93	23.3
College Graduate	261	65.3
Other	14	3.5
Prefer Not to Say	3	0.8

### **Statistical Results**

A total of 400 participants aged 18 years or older participated in the Google Forms Organ Donation Research Questionnaire. The survey included 18 questions that captured demographic information; addressed knowledge and common beliefs related to organ donation; current donor status; where participants' current knowledge about organ donation was obtained; whether or not having an opportunity to receive education about organ donation from a healthcare provider

would be beneficial; and possible religious, spiritual, or personal beliefs that influence the individual to support or not support organ donation in any way. Data from the completed surveys was then subjected to analysis using the Statistical Package for Social Sciences (SPSS) 26 statistical software. Analyses were performed to answer the research questions. The following questions were investigated by the researchers.

## **Data Analysis**

### ***Knowledge Deficit***

Approximately 66% of the respondents scored 80% or better in the knowledge portion of the quiz (Figure 1). According to the operational definition, having a knowledge deficit regarding organ donation constitutes a score of less than 80% on the Organ Donation Research Questionnaire Tool. On the computed knowledge score, of a possible score of 100 points (10 points for every correct item), the mean score was 77.78%. Individual scores ranged from 10 points to 100 points. Performance on the knowledge questions was not significantly different by age group,  $X^2(3, N = 400) = 3.32, p = .345$ . Performance was also not significantly affected by gender,  $X^2(1, N = 400) = 0.90, p = .342$ .

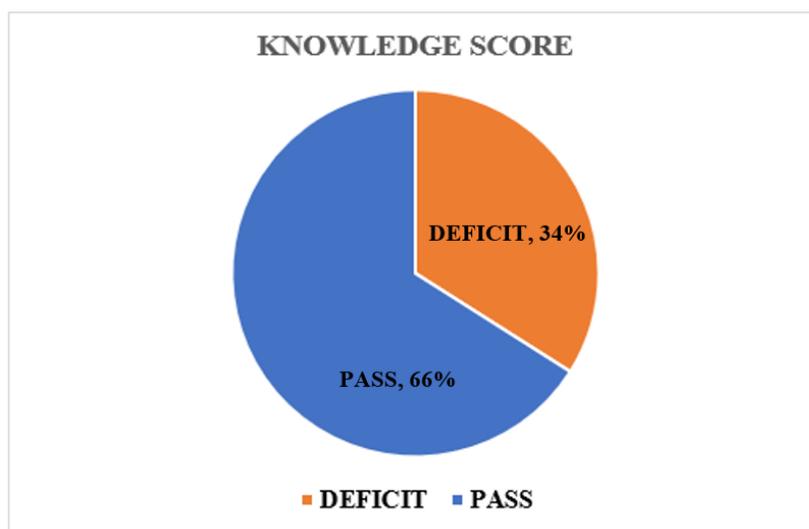
To analyze whether there was an association between race and performance on the knowledge quiz, the race variable was collapsed to a dichotomous variable. This was due to the sample being overwhelmingly Caucasian, and there were so few respondents in any of the other race categories. With the variable recoded to “Caucasian” or “other,” the results of Chi-square test of independence suggested there was a significant association between race and performance on the knowledge quiz,  $X^2(1, N = 400) = 5.37, p = .032$ . As performed with the race variable, to analyze performance on knowledge questions by education, the education variable was recoded

to “college graduate” or “other.” The results of this Chi-square test were not significant,  $\chi^2(1, N = 400) = 2.06, p = .152$ .

An analysis of each of the 10 knowledge questions was conducted (Table 2). The knowledge question in which respondents performed the best (97.5%) was knowledge question eight. This was a true or false question stating, “There are not enough organs to go around to patients who need transplants, and that is a major problem facing transplant doctors today.” Knowledge question one was the question in which respondents had the greatest knowledge deficit, with only 19.3% of respondents selecting the correct response. This was a true or false question stating, “There are no major religions that oppose organ donation.”

### Figure 1

#### *Performance on the Knowledge Questions*



*Note: A passing score of 80% or greater indicates the respondent is knowledgeable regarding organ donation. A score of less than 80% indicates lack of knowledge regarding organ donation.*

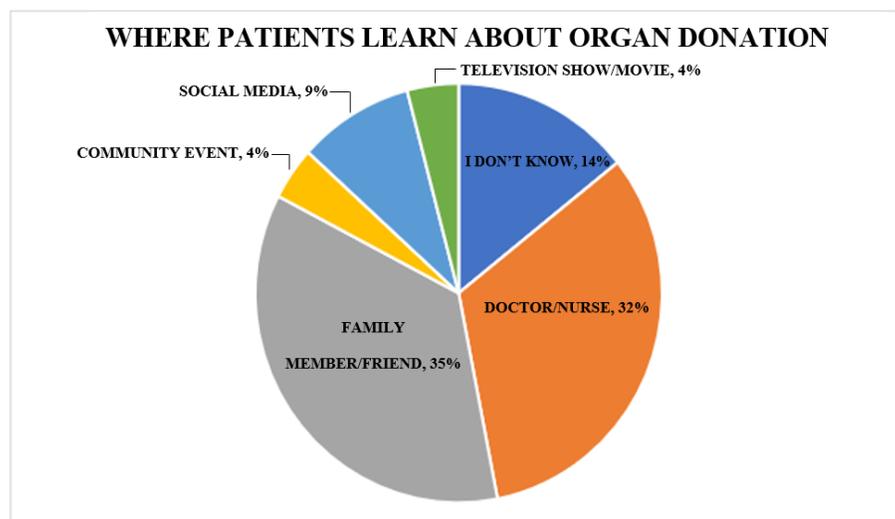
**Table 2**

*Percentage of Knowledge Questions Answered Correctly*

	<b>% selecting the correct answer</b>	<b>Rank (1 highest to 10 lowest)</b>
<b>Items</b>		
Question 1	19.3	10
Question 2	94.5	2
Question 3	75.5	8
Question 4	94.0	3
Question 5	81.5	5
Question 6	87.3	4
Question 7	76.0	7
Question 8	97.5	1
Question 9	86.0	6
Question 10	66.3	9

**Figure 2**

*Percentage of Where Adults Learn About Organ Donation*



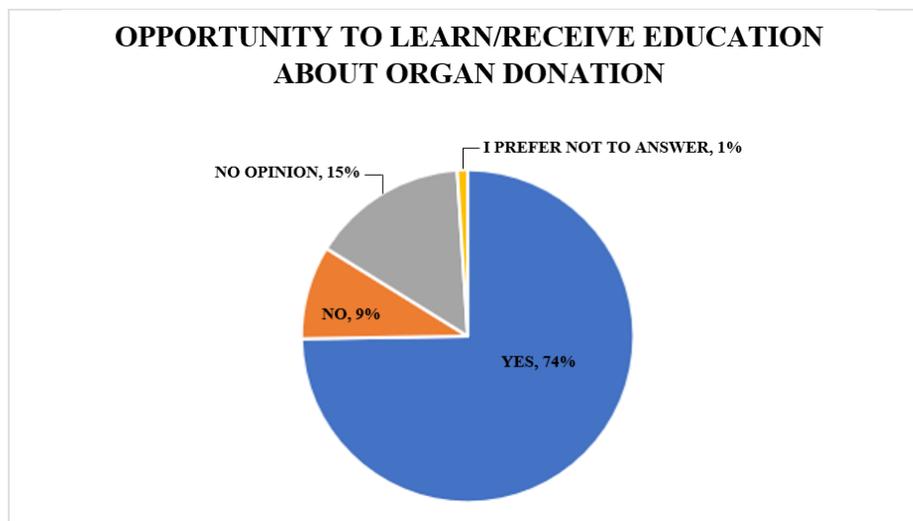
### *How Knowledge is Received*

The respondents in the sample overwhelmingly learned about organ donation from family and friends (35.55%) and primary care providers (32.5%). Figure 2 breaks down the sources where respondents received information on organ donation.

Respondents were also asked personal preference for receiving additional information about organ donation from healthcare providers. Nearly 75% of participants responded that more information would be beneficial. The breakdown of responses to the question are displayed in Figure 3.

**Figure 3**

*Opportunity for Education from Healthcare Providers Regarding Organ Donation*



### *Influences on Beliefs Regarding Organ Donation*

While beliefs about organ donation are not directly addressed by the questions asked in the survey, there is a question about organ donor status that was recoded to a dichotomous (yes/no) variable. Statistically, a positive correlation between respondents' scoring at least 80% on the quiz was found to be significantly associated with being a registered organ donor. Respondents' performance on the knowledge portion of the quiz positively correlated with being

a registered organ donor,  $X^2(1, N = 392) = 11.12, p = .001$ . Whether or not a person is a registered organ donor is not significantly associated with age group,  $X^2(3, N = 392) = 4.20, p = .241$ , gender  $X^2(1, N = 392) = 1.51, p = .219$ , race  $X^2(1, N = 392) = .296, p = .587$ , or education,  $X^2(1, N = 392) = 0.213, p = .645$ . Having religious beliefs related to organ donation was also not significantly associated with being a registered organ donor,  $X^2(1, N = 345) = 2.12, p = .145$ .

**Table 3**

*Registered Organ Donor Status (N=400)*

	<b>Number of Respondents</b>	<b>% of Respondents</b>
<b>Current Donor Status</b>		
Already Registered	346	86.5
Not Registered	46	11.5
Not Answered	8	2

The researchers included a comment box for optional reflections and feedback at the end of the survey. There was no specific trend except all comments provided positive feedback about organ donation.

### **Summary of the Findings**

This chapter presented the researchers' findings from the current quantitative study that surveyed 400 men and women participants aged 18 years and older who accessed the Organ Donation Research Questionnaire via the Google Forms link posted to social media. The results analysis revealed participants' performance on the knowledge quiz is significantly associated with being a registered organ donor. The participants have learned about organ donation mostly from family and friends and primary care providers. Participants were least knowledgeable in regard to the question about major religions that oppose organ donation. The participant sample

was highly educated, and the majority were Caucasian, which may have skewed results. Results of this analysis reveal there is a need for improvement in organ donation education.

## CHAPTER V

### Summary and Conclusions

End stage organ failure affects millions of people worldwide. In the United States, there are more than 113,000 people on the national transplant waiting list. Approximately 95% of adults in the United States support organ donation; however, only 58% are registered donors (HRSA, 2019b). Many patients on the transplant waiting list are dying while waiting to receive a transplant because there is a lack of registered organ donors. There are multiple reasons people do not register to become organ donors. A lack of education on the topic is one of the main reasons. There is inaccurate information in communities that negatively influences an individual's beliefs on organ donation. Primary healthcare providers have a unique advantage to being able to educate and provide information to patients regarding all health matters, including organ donation. Healthcare providers are viewed as trusted sources of information. According to a study by Degenholtz et al. (2019), patients are not generally provided with education concerning organ donation in the primary healthcare setting.

The purpose of this study was to determine if adults in the community lack basic knowledge regarding organ donation, how knowledge on organ donation is received, and what factors affect beliefs regarding organ donation. The findings revealed patients do have a knowledge deficit regarding organ donation, and there is a need for proper education from trusted healthcare providers. The study is useful because the study provides specific data regarding adult patients concerning organ donation. The findings allow healthcare providers to utilize statistics to develop ways to obtain and provide education.

Ajzen's Theory of Planned Behavior Model was utilized as the conceptual framework for the research study. The theory is intended to explain all human behaviors over which people may

have the ability to exert self-control (LaMorte, 2019). The theory proposes an individual's attitudes, intentions, subjective and social norms, and perceived behavioral control influence behavioral intentions. The theory is applicable to the current study because any individual has autonomy to register or not register as an organ donor. The Organ Donation Research Questionnaire tool used in this study was created to address the concepts of Ajzen's theory. The current research study aimed to answer the following questions:

1. Is there a knowledge deficit among adult patients that could affect the decision to become a registered organ donor?
2. How do adult patients receive knowledge regarding organ donation?
3. Are there identifiable factors that influence an adult patient's beliefs regarding organ donation?

A comprehensive literature review pertinent to the content of this research study was performed by the researchers. Further research needed to be done on the topic of organ donation. The literature review also showed a significant need for increased education regarding organ donation. The researchers used the information from the literature review to help develop the Organ Donation Research Questionnaire on Google Forms. The questionnaire captured demographic information, knowledge related to organ donation, where the adult's knowledge was received, current donor status, and possible influences that may have contributed to donor status. After obtaining approval from the IRB, the online link to the survey with an opening message was shared by the researcher on social media platforms Facebook and LinkedIn for adult patients 18 years and older to anonymously complete. The goal for the number of respondents was 400, which was met within a short period of time due to overwhelmingly quick

responses. Once the study was completed, the researchers retrieved data from Google Forms for analysis. Data was analyzed using descriptive statistics and correlation.

This chapter will present a narrative of the important findings of this study and provide a discussion of the findings, including a comparison of the results from this study to the studies in the literature review. The chapter will address the limitations that the researchers faced. Implications and further recommendations will also be discussed.

### **Summary of the Findings**

The demographics section of the study revealed nearly 45% of respondents were 40 years to 60 years of age. Closely, 41% of the respondents were 25 years to 39 years old. Most of the sample were females (93.3%) and Caucasian (96.5%). The sample was also highly educated, with 65.7% reporting being a college graduate.

To answer the research question, “Is there a knowledge deficit among adult patients that could affect the decision to become a registered organ donor,” approximately 66% of respondents scored 80% or better in the knowledge portion of the questionnaire. By operational definition, having a knowledge deficit about organ donation would constitute a score of less than 80% on the Organ Donation Research Questionnaire, which addressed 10 common misconceptions or myths regarding organ donation. Approximately 34% of respondents scored less than 80%, indicating a knowledge deficit among the respondents. Age and gender did not significantly affect results of this portion of the questionnaire.

For the second question, “How do adult patients receive knowledge regarding organ donation,” the respondents have learned about organ donation from family and friends (35.55%) and primary care providers (32.5%). Respondents were also asked about personal preference for

receiving additional information about organ donation from healthcare providers. Most of the participants (74.5%) responded that more information would be beneficial.

For the final research question, “Are there identifiable factors that influence an adult patient’s beliefs regarding organ donation,” the data was not directly addressed by the questions asked in the questionnaire. There was a question about organ donor status that 86.5% of respondents answered yes, they are registered organ donors, and 11.5% answered no, they are not registered organ donors. Age and religious beliefs were not significantly associated with organ donor status. Respondents’ performance on the knowledge portion of the quiz positively correlated with being a registered organ donor.

### **Discussion of the Findings**

The researchers met the goal of 400 respondents. Most of the sample being Caucasian females is possibly due to the researchers of the study being Caucasian females with more Caucasian female followers on the selected social media platforms utilized. Eighty-six percent of respondents were 25 years to 60 years of age. This could be due to the age groups most likely to utilize social media. The findings of this study were similar to those of Katz et al. (2019), which found the Theory of Planned Behavior explained that factors affecting the shortage of registered organ donors were lack of control, the need for more information, mistrust, and prosocial behaviors.

The findings of the current research are also closely related to those of Sellers et al. (2018), which determined the major factor limiting organs donated and transplants performed is lack of consent for organ donation, which is affected by knowledge deficits and myths surrounding organ donation. The study found that education dispelling common myths and misconceptions would potentially increase the number of registered organ donors, reduce

transplant waiting lists, and decrease the number of lives lost due to organ failure (Sellers et al., 2018).

The research indicates patients find discussing organ donation with healthcare providers beneficial. According to Thornton et al. (2016), healthcare providers find discussing organ donation with patients suitable, but fail to discuss organ donation secondary to lack of time. The study found that when given additional information, including an informational video regarding organ donation, and encouraged to ask a healthcare provider questions for further discussion, the patients were more likely to register as organ donors (Thornton et al., 2016). The findings correlate with findings from the current study because the current researchers determined the more educated an individual is regarding organ donation, the more likely the individual is to be a registered organ donor. The study of Natt et al. (2017) also concluded that providing education in a healthcare setting increased organ donor registration rates. Most of the reviewed literature was based on the same concept of proper education correlating with likelihood of becoming a registered organ donor, which is what the current study was able to conclude.

## **Conclusions**

The goal of the current research was to determine if adult patients in the community lack basic knowledge regarding organ donation, how knowledge about organ donation is received, and what factors affect beliefs regarding organ donation. According to the results, 34% of adult respondents have a knowledge deficit regarding organ donation. Approximately 66% of participants scored 80% or better in the knowledge portion of the questionnaire, meaning respondents are knowledgeable regarding organ donation.

The results of the survey indicated most adults receive information regarding organ donation from friends, family, and primary care providers. Nearly 75% of respondents would

prefer for healthcare providers to discuss organ donation on a routine basis with patients. While this study did not answer the research question regarding what factors affect beliefs on organ donation, there was a remarkable correlation between already registered organ donors and a higher score on the knowledge portion of the questionnaire. The findings indicate a significant need for further education of organ donation by primary care providers. If patients were better educated on organ donation, more adults may register to become organ donors. Additional registered organ donors will help to reduce the shortage of available organs for transplant.

### **Limitations**

The following limitations of the research design and methods of data analysis were identified at the conclusion of the study.

1. Inability of the researchers to perform the study in a primary healthcare setting due to the Coronavirus pandemic.
2. The method of data collection was limited to a computerized survey posted on the researchers' personal social media sites.
3. Limited sample size consisting of 400 respondents.
4. There were no questions in the questionnaire that answered the research question regarding identifiable factors that influence beliefs regarding organ donation.

The limited sample size diminished the reliability of the current research. Due to the anonymous, computerized responses and wide availability of the survey link on social media, the geographic location that was studied is unknown. Many respondents were Caucasian females and educated, thus limiting the generalizability of the research.

## **Implications**

Various implications were constructed following the conclusion of the current research. The study concluded some adult patients in the community lack basic knowledge regarding organ donation and most individuals think receiving information regarding organ donation from a healthcare provider would be beneficial. The study also provided a correlation that the more knowledgeable about organ donation a person is, the more likely the individual is to register to become an organ donor. Using the results of this study, primary care providers need to be more aware of the need for organ donation education in the healthcare setting. Providers can use specific data points to determine where the major knowledge deficits are and what areas to focus the teaching. Many medical professionals are not properly educated on organ donation while in school, so there are also implications for educating for healthcare providers.

The results of this study can be used to guide additional research in the future in terms of organ donation knowledge deficits. Replication of the current research using a larger, more diverse sample should be done to determine whether knowledge deficits regarding organ donation are the same in other populations. The current study could be performed in a clinic setting to further provide implications for healthcare providers. This study was guided by Ajzen's Theory of Planned Behavior Model, which is intended to explain all human behaviors over which people may have the ability to exert self-control. The theory was useful because the theory helped develop the questionnaire tool; and supported that being knowledgeable about organ donation (behavior) and being a registered organ donor (self-control) are closely related.

## **Recommendations**

Based on the outcomes of this study, the following recommendations are made for practice:

1. Construct an education model to display to healthcare providers and healthcare education programs regarding common myths and misconceptions concerning organ donation and proper teaching points for patients that should be addressed during routine visits.
2. Construct an additional education model to demonstrate information, including benefits and risks of organ donation and how to join the national donor registry.
3. Increase the public's awareness of the shortage of available organs for donation and the severity of the need for more registered organ donors by creating visual aides to display in clinic examination and waiting rooms.
4. Increase the number of medical professionals who provide routine organ donation education to patients and families by creating a prompt in the electronic healthcare system.

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## Appendix A

### ORGAN DONATION RESEARCH QUESTIONNAIRE

Participants must be 18 years of age or older to participate.

Please only submit the form once.

Section A. Demographic Information. Please select the answer that best suits you.

1. Please select your age group.
  - a. 18-24 years old
  - b. 25-39 years old
  - c. 40- 60 years old
  - d. 60 years and older
  - e. I prefer not to say.
  
2. Please select your gender.
  - a. Male
  - b. Female
  - c. I prefer not to say.
  
3. Please select your race.
  - a. African American
  - b. Asian
  - c. Caucasian
  - d. Hispanic
  - e. Multi-racial
  - f. Other
  - g. I prefer not to say.
  
4. What is the highest level of education you have completed?
  - a. Less than high school graduate
  - b. High school graduate or GED
  - c. Some college
  - d. College graduate
  - e. Other
  - f. I prefer not to say.

Section B: The following section will address your knowledge regarding organ donation. Please read the following true/false questions and select the answer you believe is correct.

1. There are no major religions that oppose organ donation.
  - a. True
  - b. False
  - c. I do not know.
2. Paramedics and doctors will not try as hard to save my life if they know I am an organ donor.
  - a. True
  - b. False
  - c. I do not know.
3. A famous or wealthy person who needs an organ transplant is more likely to receive a transplant than someone who is not wealthy or famous.
  - a. True
  - b. False
  - c. I do not know.
4. Organ donation prevents an open casket funeral.
  - a. True
  - b. False
  - c. I do not know.
5. A person who has been declared “brain dead” but still has a beating heart still has the chance of recovering.
  - a. True
  - b. False
  - c. I do not know.
6. Organ donation increases medical costs for the donor’s family.
  - a. True
  - b. False
  - c. I do not know.
7. A person cannot be an organ donor if they are too young or too old.
  - a. True
  - b. False
  - c. I do not know.
8. There are not enough organs to go around to patients who need transplants, and that is a major problem facing transplant doctors today.
  - a. True
  - b. False
  - c. I do not know.
9. I’m not in the best of health, so doctors cannot use my organs for donation.
  - a. True
  - b. False
  - c. I do not know.
10. Kidneys are the most commonly transplanted organ, and they are also the most needed.
  - a. True
  - b. False
  - c. I do not know.

Section C. Please select the answer that best fits you.

1. Which statement below best fits your organ donor status?
  - a. I am a registered organ donor which means I have a red heart on my driver’s license, or I have registered online.
  - b. I tell people that I am an organ donor, but I have not officially registered.
  - c. No, I am not an organ donor.
  - d. I prefer not to say.



## Appendix B

### INTERNATIONAL REVIEW BOARD APPROVAL LETTER



March 24, 2020

Dr. Terri Hamill  
 College of Nursing and Health Sciences  
 1100 College St. W-910  
 Columbus, MS 39701

Dear Dr. Hamill:

I am pleased to inform you that the members of the Institutional Review Board (IRB) have reviewed the following proposed research and have approved it as submitted:

<b>Name of Study:</b>	Knowledge Deficit of Patients Regarding Organ Donation in the Primary Healthcare Setting
<b>Research Faculty/Advisor:</b>	Terri Hammill
<b>Investigators:</b>	MSN Students

I wish you much success in your research.

Sincerely,

Scott Tollison, Ph.D.  
 Provost and Vice President for Academic Affairs

ST/tc

pc: Irene Pintado, Institutional Review Board Chairman

## Appendix C

### **ORGAN DONATION RESEARCH QUESTIONNAIRE- MSN RESEARCH PROJECT OPENING MESSAGE**

Greetings,

I, along with my fellow family nurse practitioner student researchers (names of all group members except the one posting), kindly request your participation in our 18-question survey concerning organ donation. This questionnaire is completely anonymous. We highly value and encourage your honest responses.

You will find the link to the online questionnaire below.

Thank you for your participation.

Sincerely,

(Student's name)

MSN, FNP Student

Mississippi University for Women