# IMPLEMENTATION AND EVALUATION OF A PROGRAM TO INCREASE ORGAN DONATION AMONG THE AFRICAN AMERICAN COMMUNITY

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A Doctor of Nursing Practice Quality Improvement project submitted to the faculty at the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Nursing Practice in the Doctor of Nursing Practice Program in the School of Nursing.

Chapel Hill 2021

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#### ABSTRACT

Amanda Peay: Implementation and Evaluation of a Program to Increase Organ Donation among the African American Community (Under the direction of Ashley Kellish)

**Introduction:** In the U.S., there are 112,283 candidates on the waiting list for an organ transplant and 3,472 on the waiting list in North Carolina (HRSA, 2020). The lack of organ donors in the U.S. and locally in NC is a major problem and can negatively impact candidates needing an organ transplant. *The purpose of this Doctor of Nursing Practice (DNP) project is to implement and evaluate a program to increase organ donor intentions and registration in the African American community*.

**Methods:** Using a distinct community-focused approach to promote a psychologically safe environment to learn about organ donation, participants were provided guidance on the topic from a trusted source and anonymous surveys collected data to capture the overall improvement.

**Interventions:** An online informational video conducted by a LifeShare representative, who is also a member of the congregation regarding organ donation was administered virtually over two weeks throughout May and June of 2020 and again in August of 2020. Data was collected via pre- and post-surveys before and after each informative video. Due to COVID, interventions and data collection were all completed virtually.

**Results:** There were 26 respondents that completed the pre-questionnaire survey. 100% of the respondents were African American, 19 were females and seven were males, 100% of the respondents were at least a high school graduate or had a higher education, and 13 indicated they were a registered organ donor and 13 respondents reported they were not. All 13 respondents

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who indicated they were organ donors, registered at the local DMV. Sixteen respondents reported they had informed their family members of their organ donor wishes and 10 said they had not. After watching the video, 48 respondents completed the questionnaire. Of those 48, 33 (68.75%) indicated they will sign up to become a registered organ donor and 15 (31.25%) stated they will not sign up to become an organ donor.

**Conclusion:** The outcomes of this project were measured by the change in donor intention and/or registration based on pre- and post-survey results after watching an online informational video on organ donation and proven to be an effective intervention tool.

#### ACKNOWLEDGEMENTS

First, I would like to thank God for keeping me and helping me get through my trials and tribulations, while attending this DNP program at UNC-Chapel Hill. Thank you, Dr. Ashley Kellish, for serving as my committee chair for this DNP quality improvement project. I am so grateful and appreciative of your constant guidance and encouragement. Thank you, Dr. Carrie Palmer and Dr. Julie Page, for serving as my committee members. Your assistance and feedback on this DNP project have been greatly appreciated. I would also like to thank my church members and Pastor Dr. Haven O. Anderson, of Marvin AME Zion church for assisting me and allowing me to use the church as the setting to implement this quality improvement project.

Lastly, I would like to thank my family and special friends, who have kept me encouraged. I would like to specially thank my children, Tim, Sydney, and Kamran, for being patient with me as I have continued to embark on achieving my goals and striving for success. I do this for you all, for you all will see sky's the limit. You guys can do anything you put your mind to. Just know nothing comes easy, you must work for it.

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# LIST OF ABBREVIATIONS AND SYMBOLS

AA African American

AL	Alabama
β	beta
CTRL	control
DMV	Department of Motor Vehicle
DNP	Doctor of Nursing Practice
F/U	follow-up
GA	Georgia
HRSA	Health Resources and Services Administration
NC	North Carolina
р	p-value
QI	Quality Improvement
TPB	Theory of Planned Behavior
US	United States

#### **CHAPTER 1: INTRODUCTION**

In the United States (U.S.), currently there are 112,283 candidates on the waiting list for an organ transplant and 3,472 on the waiting list in North Carolina (NC) (HRSA, 2020). From January to December of 2019, there were 19,253 organ donors recovered including both deceased and living donors from all ethnicities in the U.S., and only 2,414 of the donors recovered were African American (HRSA, 2020). In NC there were 554 donors recovered, both living and deceased, and amongst the 554 donors recovered only 93 were African Americans (HRSA, 2020). The lack of organ donors in the U.S. and locally in NC is a major problem and can negatively impact candidates needing an organ transplant (HRSA, 2020 & DuBay et al., 2019). Approximately, 22 people die each day waiting on an organ transplant in the U.S. (DuBay et al., 2019). It is noted that minorities disproportionately have lower rates of organ transplantation, despite having the highest rate of risk factors for increasing the need of an organ transplant (HRSA, 2020).

An engaged health ministry team in an African American Church in a rural area of NC discussed the issue of African Americans having the highest need for organ transplantation in NC. Currently there are 1,566 African Americans on the waiting list for an organ transplant in NC compared to 1,299 Caucasian candidates (HRSA, 2020). There are 32,281 African American candidates on the waiting list for an organ transplant in the U.S. with the highest need of 30,060 waiting on a kidney (HRSA, 2020). The goal as health ministry members is to continue to bring awareness to the African American community, educate, and conduct interventions to decrease risk factors that African Americans face in the United States today.

The reasons African Americans may be more reluctant to become an organ donor are a lack of knowledge and awareness, cultural/religious beliefs, distrust in the healthcare system, fear of medical abandonment and fear of racism (Bratton et al., 2011). The purpose of this Doctor of Nursing Practice (DNP) project is to *implement and evaluate a program to increase organ donor intentions and registration in the African American community*.

#### **CHAPTER 2: LITERATURE REVIEW**

PubMed and CINAHL were the main databases utilized for this literature review, using the search terms ((("organ donation" OR organ donor)) AND African Americans) AND (mistrust OR culture OR cultural OR awareness OR knowledge OR barriers OR qualitative)); ((((((("organ donation" OR organ donor)) AND African Americans)) AND (education or intervention or pilot or random\*)) date range 2008 through 2019 in order to review the effectiveness of current programs, achieve the most up to date statistics of organ donation among African Americans, and retrieve the current number of candidates on the waiting list for an organ. Federal and non-profit organization websites were also reviewed for related information including HRSA, Donate Life NC and LifeShare Carolinas.

Inclusion criteria included full text information available focused on (1) African Americans and organ donation intentions; (2) African American attitudes/beliefs, distrust in the health care system, fear of medical abandonment and racism, and knowledge regarding organ donation; and (3) interventions to increase organ donor registration among African Americans. Studies were excluded if they consisted of focusing on one specific organ; such as, kidneys only. Any studies conducted outside of the United States were excluded. In addition, studies regarding any other races outside of African Americans were excluded. Finally, studies that targeted only one particular group of African Americans (men, women, or clergy only) and the interventions were the same as all of the other studies were excluded as well. Thirty-six references were found in the initial search. There were 12 duplicates. Twentyfour were screened. Six studies consisted of Haitian, Caucasian and Hispanic races, eight studies focused on only one specific organ and not all organs, two studies were conducted outside of the United States, one study consisted of African American men only, and another study consisted of African American clergy only. Six studies met inclusion criteria and read for full text review. Data were extracted using the Matrix Method tool (Appendix 1), which was used to synthesize the studies. Primary outcome measures were organ donor intentions and registration among African Americans. Secondary outcome measures were knowledge and awareness of organ donation, religion and beliefs, distrust in the healthcare system, familial notification, and racism and fear of abandonment. The results have been critically appraised for strength, consistency, reliability and validity. Some limitations of the search were some of the studies consisted of self-reported data and some of the studies measured organ donor intentions versus organ donor registrations, which were unobservable and unreliable.

#### Results

## Problem

There were four studies identified addressing why African Americans are reluctant to become organ donors (Bratton et al., 2011; DuBay et al., 2019; Robinson, Klammer, Perryman, Thompson, & Arriola, 2014; Robinson, Perryman, Thompson, Lamonte Powell, & Jacob Arriola, 2015). Each study explored variables, such as, family notification, religion and beliefs, distrust in healthcare system, and knowledge and awareness. Two of the studies, (Robinson et al., 2015) and (Robinson et al., 2014), consisted of cross sectional designs and used the same sample of a larger study and the data collection method was a self-reported survey. The level of evidence for both studies were considered lower quality due to potential for bias as participants were recruited from personal social networks; however, the studies were considered valid with

strengths of having a moderate sample size at least 500 participants and the study population was representative of the study. Both of the studies measured the outcomes the same way and concluded that religious norms (anti-donation religious stance) were the most significant and consistent correlate of willingness to donate and written expression of donation intentions (driver's license or donor card) (Robinson et al., 2014). It also concluded that physician trust ( $\beta = 0.49$ ; p = 0.00) and trust in the donation/allocation system ( $\beta = 0.11$ ; p = 0.02) were each significantly associated with attitudes toward donation (Robinson et al., 2015).

A qualitative study by (DuBay et al., 2019) used a self-reported post questionnaire to explore the experiences of familial notification among recent African American registered organ donors obtained from the Department of Motor Vehicle (DMV) and identify ways to overcome potential barriers to the notification process. It was considered a lower quality level of evidence as a result of its small sample size; however, the study was considered valid as the population was representative of the study. The analysis of the study focused on motivation for the notification, notification conversation, and promoting familial notification. Findings revealed that participants were concerned about their own lack of knowledge regarding organ donation, their family's lack of understanding, or religious beliefs, such as, wholeness of the human body and that God can heal body parts without an organ transplant. Other findings indicated that some chose not to disclose their organ donor decision as they felt it was a private decision and personal matter, and some felt their families would not approve. Overall, the study findings concluded that participants valued familial notification and encouraged the use of social media in facilitating the notification process. In addition, the way one perceives one own self and expectations played an influential role in familial disclosure regarding organ donation.

A systematic review (Bratton et al., 2011) resulted in high quality level of evidence and low risk of bias. In this study, a meta-analysis of the associations between organ donation, racial disparities, and barriers were analyzed. The outcomes identified barriers; such as, decreased awareness, distrust of healthcare providers, and racism and fear of abandonment from the medical field. Results identified five key barriers to deceased organ donation, which were 1) lack of transplantation awareness, 2) religious beliefs and misperceptions, 3) distrust of the healthcare community, 4) fear of premature declaration of death after signing a donor card, and 5) fear of racism. Additional results analyzed, determined that African American men were least willing to become organ donors secondary to religious beliefs. Other findings from the systematic review indicated that African Americans compared to Caucasians were significantly less willing to donate organs or another's organs due to an overwhelmingly amount of lower levels of discrimination and mistrust in the healthcare system.

#### **Solutions**

Two studies reported on the effectiveness of educational interventions in increasing organ donation registrations and intentions (DuBay et al., 2019; Arriola, Robinson, Thompson, & Perryman, 2010). One study evaluated the use of an educational video at several DMVs on donor registration. The results showed that an increase in organ donor registration was consistently observed in each DMV while the video was on compared to off (mean= +2.3%) and the video was equally effective in Caucasians and African American. In the addition, organ donor registration was observable and a reliable measure (DuBay et al., 2019).

Another study tested the effectiveness of an educational intervention at an African American church to increase readiness for organ donation. They reported there was a baseline of 425 participants and 337 of the participants completed a one-year follow-up survey. The control group received currently available educational material for consumers regarding organ donation

and the intervention group received Project ACTS (About Choices in Transplantation and Sharing) educational material. The primary outcomes evaluated at one-year follow-up were readiness to express donation intentions via driver's license, donor card, and discussion with family. Findings of the study based on Prochaska's Stages of Change (i.e. action or maintenance) indicated the intervention group were 1.64 times more likely to be in the action or maintenance stage in their readiness to have a family discussion regarding organ donation intentions at followup compared to the control group (p = .04), participants were 1.53 times more likely to be in the action or maintenance stage for readiness to carry a donor card than at baseline (p = .01), and there were no significant effects of condition or condition by time on readiness to be identified as a donor on driver's license and by carrying a donor card (Arriola et al., 2010). In this study, organ donation intentions are unobservable, and therefore, unreliable. However, the study is valid and the strengths of the intervention were cultural sensitivity, representative population, and a moderate sample size. Both studies were high quality and low risk for bias.

#### **Summary**

Based on the body of evidence, the quality of the studies reviewed are moderate to high quality. Although some studies may have had a higher risk of bias, there were sound study designs and validity of the outcome measures. All of the studies met inclusion criteria identified sufficiently and support the need to influence the African American community in order to increase organ donation through a safe and respected area such as their local church.

#### **CHAPTER 3: THEORETICAL FRAMEWORKS**

The Theory of Planned Behavior (TPB) is a behavioral theory proposed by Ajzen and Fishbein in 1975 and 1980 to predict and explain health behaviors and intentions as well as to aid in interpreting study findings (Glanz, Burke, & Rimer, 2018). Therefore, TPB is descriptive, explanatory, and predictive in its use. The TPB makes a central assumption that behavioral intentions are essential determinants of behavior (Glanz et al., 2018).

The six constructs of TPB are *attitudes, behavioral intentions, subjective norms, social norms, perceived power,* and *perceived behavior control. Attitudes* examines the extent to which a person has a favorable or unfavorable evaluation of the behavior of interest. For example, examining attitudes consists of exploring the reasons *why* African Americans are reluctant to become organ donors. *Behavior intentions* are the motivational factors that influences a behavior. Behavior intentions helps to predict if the behavior will occur or not; the stronger the intention to donate organs, the more likely it will occur. *Subjective norms* are the beliefs about how others approve or disapprove of the behavior. With regards to subjective norms, individuals may seek the opinion of others whom they deem as important (i.e. family members, peer, pastors) whether they should become an organ donor or not. *Social norms* are normal codes of behavior in group or cultural context. If it is the social norm for African Americans from cultural aspect to not donate organs, then it will not be perceived as a problem or important to change. *Perceived power* is perceived presence of things that may aid or inhibit performance of the behavior; and *perceived behavior control* is the final construct that was added last and shifted Theory of Reasoned Action to Theory of Planned Behavior (Glanz et al., 2018; Behavior Change Models, 2019). Perceived behavior control is the individual's perception of the ease or difficulty of performing the behavior of interest. For instance, African Americans may feel motivated to donate organs, if they believe they can do it (Behavior Change Models, 2019; Glanz et al., 2018).

The Theory of Planned Behavior fits with the metaparadigm of nursing by looking at humans as individuals and their uniqueness. It considers an individual's societal beliefs, values, and morals. Also, in line with nursing, it encompasses the perception of health and wellness and combined with a need to advocate, it supports a nurse's instinct to improve healthcare and create change (Butts, 2018).

The Theory of Planned Behavior has helped to guide this DNP project in order to successfully create behavior change in African American community. African Americans' reluctance to become organ donors and their disproportionately lower rate in organ transplantation among other races has contributed to this disparity. With the framing provided by the TPB, this project can assess and identify attitudes and beliefs, and subjective norms regarding the reluctance of organ donation in the African American community (Hyde & White, 2010). In a study conducted by (DuBay et al., 2014), there was an emphasis on how the TPB informed identification of factors associated with organ donation among the African American community; such as, religious beliefs and distrust in the healthcare system.

The TPB offers a descriptive approach for the identification of noticeable behavioral influences, which is an essential first step in the design of relevant interventions (Young, Lierman, Powell-Cope, Kasprzyk, & Benoliel, 1991). Furthermore, the TPB is particularly helpful when designing educational programs intended to change specific health behavior by taking into account one's beliefs, attitudinal factors, and subjective norms, which are secondary

outcomes of this DNP Project (Bastable, 2019). As such, when looking at factors causing the problem, the TPB has helped to shape the intervention of the informational sessions conducted in collaboration with LifeShare, an organ procurement organization.

The Iowa Model (2015) (Appendix 5) was utilized to provide the framework of this DNP quality improvement project. The Iowa Model (2015) helped to identify the problem on a national and local level, *the lack of organ donors in the U.S. and locally in NC is a major problem and can negatively impact candidates needing an organ transplant*, the purpose (*implement and evaluate a program to increase organ donor intentions and registration in the African American community*), key stakeholders, literature review, design and methodology, and results.

#### **CHAPTER 4: DNP PROJECT PLAN**

#### Design

The primary goal of this quality improvement project was to implement informational sessions in African American communities using a psychologically safe approach in order to increase organ donor intentions and registrations among African Americans. The design included a multi-model approach to reach African Americans by trusted leaders in their community with specific information regarding organ donation. A survey was utilized before and after the informative informational video session.

#### **Setting and Population**

This DNP Project targeted a large, rural African American-based church in North Carolina. The church has approximately 350 active members. Participants were adults over 18 years of age. All participation was voluntary and survey responses were anonymous.

#### Methods

An online informational video recording conducted by both a member of the congregation and a LifeShare representative regarding organ donation was administered virtually over two weeks throughout May and June of 2020 and again in August of 2020. Data was collected via pre- and post-surveys before and after each informative video. Due to COVID, interventions and data collection were all completed virtually. The intervention utilized an informational video uploaded to YouTube which was created by a LifeShare representative; this person is also an African American member of the church to help maintain a psychologically safe place and help reduce some of the anxieties, fears, and distrust African Americans have in

the healthcare system. The informational session was administered weekly for two weeks continuously sent via mass email and took place in May-June 2020. However, due to a low response rate, the informational video and post-questionnaire was re-administered in August 2020 for two consecutive weeks.

#### **Data Collection Instruments**

Data was obtained from the pre- and post-questionnaire surveys. The pre-questionnaire survey collected baseline data and consisted of eight questions. Specific variables included: demographics, such as, age, race, gender, highest level of education, whether they were registered organ donors or not, if they were which method did, they use to sign up, if they would ever consider signing up if they were not an organ donor, and if a family member had been informed of the organ donor wishes. Post-questionnaire survey consisted of the same eight questions as the baseline survey to determine if the intervention of the informational video was successful in gaining more organ donors.

#### Results

There were 26 respondents that completed the pre-questionnaire survey (Table 1), of which 100% were African American, 19 were female, seven were male, 100% had at least a high school graduate or had a higher education, 13 were registered organ donors and 13 were not. All 13 respondents who indicated they were organ donors, registered at the local DMV. Sixteen respondents reported they had informed their family members of their organ donor wishes and 10 said they had not. After disseminating the video, 48 respondents completed the post-questionnaire survey (Table 2). Of those 48, 33 (68.75%) indicated they intend to become a registered organ donor and 15 (31.25%) stated they will not sign up to become an organ donor. Twenty-five respondents reported they would consider registering as an organ donor in the future

and nine stated they will not. Twenty-nine respondents specified they will sign up at the local DMV, two stated they will

Question	Pre-Survey %
	26 Respondents
How old are you?	$\geq$ 55 years of age – 65.38%
	35-54 years of age – 30.77%
	18-21 years of age – 3.85%
What is your race?	African American - 100%
	Hispanic – 0.00%
	White – 0.00%
	Other – 0.00%
What is your gender?	Male – 26.92%
	Female – 73.08%
Highest level of education completed?	Less than high school – 0.00%
	High school graduate/GED – 3.85%
	Some college – 7.69%
	College graduate – 88.46%
#8 - Have you signed up to become a	Yes - 50%
registered organ donor?	No - 50%
#9 - If your answer is Yes to Question	Advance Directive – 0.00%
#8, how did you sign up?	Local DMV – 100.00%
	Organ Procurement Organization
	(LifeShare, Donate Life) – 0.00%
#10 – If you did not register as an	Yes - 50%
organ donor, would you consider	Maybe – 37.50%
registering to become an organ donor	No-12.50%
in the future?	
#11 – Did you inform your family	Yes - 61.54%
member of your organ donation	No - 38.46%
wishes?	

Question	Post-Survey %
	48 Respondents
How old are you?	$\geq$ 55 years of age –26%
	35-54 years of age 21%
	18-34 years of age -0%
What is your race?	African American - 100%
	Hispanic – 0.00%
	White – 0.00%
	Other – 0.00%
What is your gender?	Male – 23.40%
	Female – 76.60%
Highest level of education completed?	Less than high school – 2.08%
	High school graduate/GED – 2.08%
	Some college – 14.58%
	College graduate – 81.25%
Will you sign up to become a	Yes - 68.75%
registered organ donor?	No-31.25%
If you answered yes to the previous	Advance Directive – 5.88%
question, how do you intend to sign	Local DMV – 85.29%
up? Please choose one:	Organ Procurement Organization
	(Lifeshare, Donate Life) – 2.94%
	IPhone Heart APP - 5.88%
If you did not register as an organ	Yes - 73.53%
donor, would you consider registering	No-26.47%
to become an organ donor in the	
future?	
Did you inform your family member of	Yes - 64.58%
your organ donation wishes?	No-35.42%

 Table 2: Post-Questionnaire Survey Results

sign up via advance directives, one reported they will sign up through an organ procurement organization, and two stated they will sign-up through the iPhone Heart App. Thirty-one respondents stated they will inform their family members of their organ donor wishes and 17 reported they had not.

The outcomes of this project were measured by the change in donor intentions based on pre- and post-survey results after watching an online informational video on organ donation. The expectation of this project is that it would be an increase organ donor registration, which will help save lives of people of all ages, genders, races, creeds, and color. The outcomes were proven successful as there was an increase in the number of respondents indicating they would become a registered organ donor. The informational video is a convenient and straightforward tool that could be implemented by health ministries or other medical teams in African American churches throughout the country. For sustainability, an assigned liaison or leader from the health ministry team of this church could be over community outreach introducing this tool to other African American churches, at health fairs, and other events; therefore, this intervention could be sustained by continuing to provide informational sessions in the African Community at health fairs and other African American churches and events.

#### **CHAPTER 5: DISCUSSION**

The pre-survey results collected baseline data on how many African American church members were registered organ donors, how many were not registered organ donors, and how many had informed their family members of their organ donor wishes. The pre-survey results also indicated the method in which the registered organ donors had signed up. Members who indicated they were registered organ donors were asked not to continue participating in the study. The post-survey results determined the number of church members who intended to become registered organ donors, the method in which they intended to sign up, and how many will inform their family members of their organ donor wishes. Results of this study had similar outcomes with the study conducted by DuBay et al. (2019). In comparison, the study utilized an educational video at several DMVs on donor registration and had proven successful outcomes with the educational video intervention. There are no opportunity costs associated with this informational video intervention. This intervention is cost-effective, and the video could be updated as data and information changes.

#### **Key Stakeholders**

LifeShare, the Pastor of the church, and the Health Ministry Team were the key stakeholders for success in this project. The Health Ministry team consisted of doctors, pharmacists, nurses, nurse practitioners, social workers, and other health care professionals. The key stakeholders assisted with the implementation of this DNP project by facilitating the organizational structure, assisting with dissemination of the information and participant buy in.

#### **Barriers and Limitations of DNP Project**

A major limitation of this DNP Project was the inability to conduct the intervention faceto-face and/or offer in-person focus groups due to the COVID-19 pandemic. A face-to-face format would have allowed for participants to ask questions and would allow participation by members without access to technology. In addition, based on the literature presented, gaining trust and by-in from the African American community in regards to health concerns is hugely valuable to promote behavior change.

Another barrier that could possibly have occurred and cause an impact of the project could be lack of participation and/or engagement due to distrust in the healthcare system. Distrust in the healthcare system has dated back over 100 years and is a result of racism. Historical medical abuses such as, the Tuskegee Syphilis Experiment contributed to African Americans' distrust in the healthcare system. Furthermore, African Americans fear whether physicians would readily try to save an organ donor's life or whether the potential organ donor would be declared deceased prematurely in order to obtain organs (Russell, Robinson, Thompson, Perryman, & Arriola, 2012).

Establishing trust as a health care provider is vital within the African American community. One study concluded that physician trust ( $\beta = 0.49$ ; p = 0.00) and trust in the donation/allocation system ( $\beta = 0.11$ ; p = 0.02) were each significantly associated with attitudes toward donation (Robinson, Perryman, Thompson, Lamonte Powell, & Jacob Arriola, 2015). Therefore, it is imperative for the intervention to be delivered face-to-face and/or presented by an African American in a culturally sensitive manner (Bratton et al., 2011). Addressing this barrier included enlisting church members, who are representatives for LifeShare, to help deliver and pre-record the online informational session. Furthermore, all of the members of the Health

Ministry team are African American, one has had a transplant, and one team member is a respected physician and deaconess in the church.

Although organ donor registration and intentions were measured, measuring donor intentions could have impacted the effectiveness of this project. Measuring intentions are unobservable and self-reported and therefore, can be difficult to measure. This issue was to be addressed by measuring organ donor intentions by using formal means, such as, driver's license, donor registries, an organ donor card, and/or a living will or health care directive (Korda, Wagstaff, & McCleary, 2007); however, as a result of the current COVID-19 pandemic, only responses given on the post-questionnaire survey were measured.

## Funding

This DNP Project will not require any outside funding. LifeShare provided pre-existing power point presentations and toolkits needed for the informational session.

#### **CHAPTER 6: CONCLUSION**

Organ donor shortage is a major problem in the United States. With more than 112,000 candidates on the waiting list for an organ transplant, the severe acute respiratory syndrome coronavirus-2, also known as COVID-19, could lead to increased waitlist mortality. As a result of the COVID-19 pandemic, it has become priority to ensure to select uninfected donors to transplant uninfected recipients as it is contraindicated for positive COVID-19 deceased patients to be considered for organ donation (Galvan et al, 2020; Shah et al, 2020). The pandemic has added a layer of complexity as health care systems has not yet developed a standard approach to evaluate donors and recipients with possible COVID-19 (Galvan et al., 2020).

It is more important than ever to educate people on registering as organ donors, with more focus on educating the African American community rather sooner than later due to COVID-19 virus. African Americans are at a higher risk for needing an organ transplant due to co-morbidities yet are the most reluctant group to register as organ donors. Although, there were not as many respondents as anticipated due to the COVID-19 virus and an elderly church population, the informational video regarding organ donation, can be an effective tool to increase awareness of organ donation. It is a convenient and direct way to target the African American community and could be more effective if given face-to-face. This tool can be implemented and sustained in a variety of settings and can help break barriers in the African American community and start saving lives with candidates waiting for an organ transplant by changing non-organ donors to registered organ donors.

# **APPENDIX 1: TABLE OF CRITIQUE ARTICLES**

Title: Organizing and Critiquing Articles Related to Organ Donation among African Americans

**Problem Statement:** The lack of organ donors in the nation and locally in NC is a major problem and has negatively impacted candidates needing an organ transplant.

Purpose Statement: Implement and evaluate a program to increase organ donor intentions and registration in the African American community.

Citation	Purpose Aims Objectives	Study Design/ Method	Study Sample/ Setting	Major Variables (outcome variables)	Measurement of variables	Analysis	Results/ Findings	Quality of the Evidence
(Arriola et al., 2010)	To test the effectiveness an educational intervention to increase organ donation intentions among AA	RCT; 9 AA churches randomly assigned: 5 church assigned to ctrl group (received donation education materials pamphlets and videotapes that were already available) and 4 churches assigned to intervention group (received the Project ACTS video and written	425 participants; AA church	Readiness to donate	Post questionnaire based on the transtheoretical model & stages of change; Donate intentions were unobservable; as the study was an assessment related to the intentions and based off a self-reported questionnaire and as such, unreliable	Analyzed via $\chi^2$ statistics to determine confounding variables differed by condition and logistic regression Outcome analysis used generalized estimating equations	Baseline-425 participants, 337 completed 1-year f/u survey. Intervention (n=175)/ Ctrl (n=162); intervention group were 1.64 times more likely to be in action or maintenance at f/u than ctrl group ( $p$ =.04); effect size small (OR <2), but still significant	Based on Melnyk & Fineout- Overholt level of evidence- Level II (Levels of Evidences, 2019) Strengths: Intervention culturally sensitive; population representative of the study; adequate sample size Weakness: participants were given the material to take home; as such, some could not

material); 1- year follow- up		have watched it; intervention mainly focused on religious beliefs

(Bratton	To review the	Systematic	11 studies	Barriers in	Via other studies	Via Statistical	AA make up	Based on
et al.,	impact of organ	Review;	were	AA to	identified by the	Meta-analysis	12.9% of US	Melnyk &
2011)	donor shortage,	inclusion	reviewed	become an	author; measured		population, 34% of	Fineout-
	racial disparities,	criteria was		organ	barriers to organ		the kidney	Overholt level
	barriers; and if	African-		donor and	donation and		transplant waiting	of evidence-
	educational	Americans,		organ	measured donor		list are AA, but	Level I (Levels
	intervention is	deceased and		donor	registrations and		only 13.8% of	of Evidences,
	important in	living donors		registration	attitudes after		deceased donors.	2019)
	helping to increase				interventions via		Identified Barriers	
	organ donor				quasi-experimental		to AA deceased	Strengths:
	registration				studies		donation:	multiple studies
							decreased	were included;
					Systematic		awareness,	population
					reviews are more		religious, distrust	representative
					objective, less risk		of healthcare	of the study,
					of systematic		providers, fear of	Meta-analysis
					errors, high quality		abandonment from	conducted,
					and therefore		medical field and	individual
					reliable		fear of racism	studies were
								clearly defined
								(characteristics,
								data, findings,
								interventions)
								Weakness:
								although article
								was completed
								in 2012, the
								data presented
								regarding
								statistics were
								from 1999 to
								2008;

(D.	To increase organ	A video was	162.387	Outcome	Organ donor	fixed effects	Increased in organ	Level of
DuBay et	donor registration	presented via	patrons	Variables:	registration was	logistic	donor registration	Evidence-a QI
al., 2019)	at the DMV via 10	an	visited 6	Organ	observable and	regression	were consistently	study not
ul., 2017)	min educational	interrupted	regional	donor	therefore a reliable	used to analyze	observed in each	intended to be
	video	time series	DMVs in	registration	measure	data;	DMV while the	generalizable
	video	design,	Alabama	registration	measure	uata,	video was on	generalizable
		repeating on	(Caucasian				compared to off	Weakness:
		2 months,	39.59%				(mean = +2.3%).	there was no
		off 2 months	AA; 1.7%				54.91% There was	sound to the
		on TVs; 12-	Hispanic;				no video-	video while it
		month study.	unknown				dependent effect	was playing;
		A QI study	3.8%)				on registration	DMV staff
		II QI Study	5.070)				between Whites	were
							and Black	familiarized
							Americans	with the study,
							(p=0.62)	which may
							(p=0.02)	have caused
								bias, which
								could minimize
								the
								effectiveness of
								the video;
								Population did
								not target only
								AA
								1111
								Strengths: the
								design allowed
								a comparison
								population of
								demographics
								prior to and
								after the video
								intervention;
								Large sample
								size; Being able
								to obtain 6
								months of
								control baseline
								data and data

int	fices not rolled in the ervention; expensive ervention

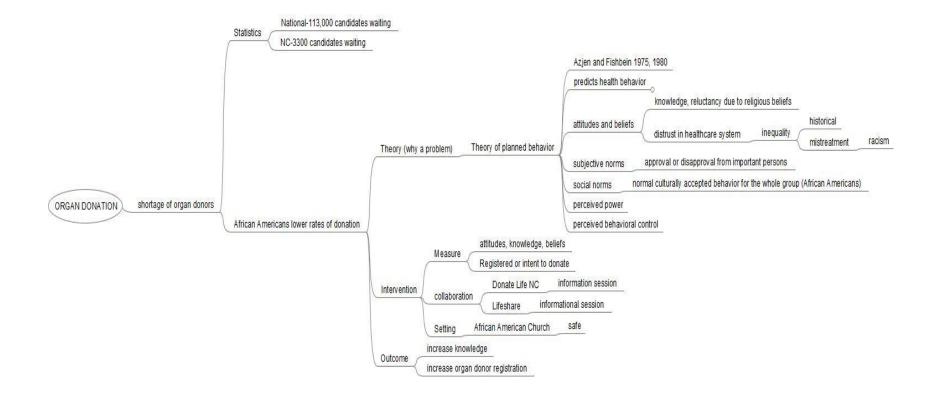
(D. A. DuBay et al., 2019)	To explore the experiences of familial notification among recent AA registered organ donors and identify ways to overcome potential barriers to the notification process	Qualitative study/ focus group approach	50 AA participants (19 years and older, men and women) whom visited the DMVs in Alabama	Outcome Variable: Notification family members about their decisions to become a registered organ donor	7 focus groups of 50 AA participants that registered as organ donor, given a questionnaire Questionnaire is self-reported; as such; unobservable; unreliable	Digitally recorded focus group discussion was transcribed & an analyzed using inductive thematic analysis, a multifunctional software system for qualitative data analysis, NVivo10, used to organize data coding process	Findings revealed that AA registered organ donors recognized the importance of notifying family, but remained reluctant to let them know	Based on Melnyk & Fineout- Overholt level of evidence- Level VI (Levels of Evidences, 2019) Strengths: population representative of the study, moderate sample size Weakness: Not generalizable due to experiences of AA from Alabama may or may not be representative to the US AA as whole
(Robinson et al., 2014)	To find the complexities of beliefs/religion, with intent to donate organs in AA	Cross- Sectional Study	585 AA participants; however only 505 participants who identified as Christians were included/ Local community	Outcome Variable: Donation intentions among AA	Survey measures consisted of religious service attendance, subjective religiosity (how religious would you say you are?), spirituality (how spiritual would you say you are?), religious norms (I	Outcomes variables measured using bivariate analysis and a logistic regression model	Results revealed religious norms (anti-donation religious stance) was the most significant and consistent correlate of willingness to donate and written expression of donation intentions	Based on Melnyk & Fineout- Overholt, level of evidence- Level VI (Levels of Evidences, 2019) Strengths: population representative

center, local business, churches, private residence in Atlanta, GA	have been taught that organ donation is against my religion?), willingness to serve as an organ donor, donation intentions, and demographics; Donation intention unobservable; however, the survey method utilized is valid	(driver's license or donor card); subjective religiosity remained significantly positively associated with willingness to serve as an organ donor ( $p < .001$ ). on the full model	of the study, moderate sample size Weakness: selection bias as participants were recruited from personal social networks; did not clearly defined denomination of Christian (i.e. AME, Baptist, non- domination, etc.), overrepresented by females with

(Robinson	To unravel the	Cross-	585 AA	Outcome	Survey consisted	Outcomes	Findings showed	Based on
et al.,	construct of trust	sectional	adults,	Variable:	of attitudes/beliefs,	variables	Physician trust (β	Melnyk &
2015)	by dividing	research	Atlanta, GA	attitudes	trust in	measured	= 0.49; p = 0.00)	Fineout-
	measures related to	design,		towards	donation/allocation	using bivariate	and trust in the	Overholt, level
	the trust in	combining		donation	systems, physician	analysis and a	donation/allocation	of evidence-
	healthcare system,	baseline data			level trust, and	logistic	system ( $\beta = 0.11$ ; p	Level VI
	trust in	from both			demographics; the	regression	= 0.02) were each	(Levels of
	donation/allocation	intervention			authors gave	model	significantly	Evidences,
	system, and trust	and control			examples of their		associated with	2019)
	with physicians;	groups;			questions for each		attitudes toward	
	and determine the	survey data			area;		donation.	Strengths:
	relationship of	gathered of			The survey did			population
	these areas to	585 AA			have validity			representative
	attitudes toward	adults						of the study,
	organ and tissue							moderate
	donation among							sample size
	AA							
								Weakness:
								selection bias
								as participants
								were recruited
								from personal
								social
								networks;
								participants;
								overrepresented
								by females with
								higher income
								brackets

**Legend:** AA (African American); AL (Alabama); CTRL (control); DMV (Department of Motor Vehicles); F/U (follow-up); GA (Georgia); QI (Quality Improvement); US (United States)

## **APPENDIX 2: CONCEPT MAP**



# **APPENDIX 3: PRE-QUESTIONNAIRE SURVEY**

1. How old are you?

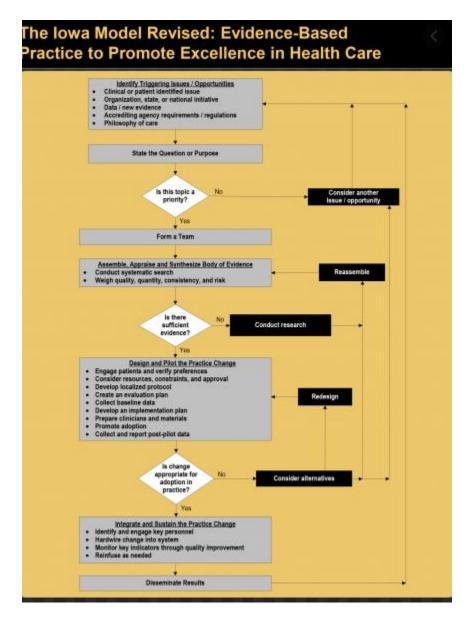
- 2. What is your race? Please choose one: African American Hispanic White Other
- 3. What is your gender? Please choose one: Female Male
- 4. Highest level of education completed? Please choose one: <high school; high school diploma/GED; Some College College Graduate
- 5. Have you signed up to become registered organ donor? Yes or No
- 6. If your answer is **YES** how did you sign up? Advance Directive, Local DMV or Organ Procurement Organization (Lifeshare, DonateLife)
- 7. If you did not register as an organ donor, would you consider registering to become an organ donor in the future? Yes or No
- 8. Did you inform your family member of your organ donation wishes? Yes or No

# **APPENDIX 4: POST-QUESTIONNAIRE SURVEY**

1. How old are you?

- 2. What is your race? Please choose one: African American Hispanic White Other
- 3. What is your gender? Please choose one: Female Male
- 4. Highest level of education completed? Please choose one: <high school; high school diploma/GED; Some College College Graduate
  - 5. Did you sign up to become registered organ donor? Yes or No
  - 6. If your answer is **YES** how did you sign up? Advance Directive, Local DMV or Organ Procurement Organization (Lifeshare, DonateLife)
  - 7. If you did not register as an organ donor, would you consider registering to become an organ donor in the future? Yes or No
  - 8. Did you inform your family member of your organ donation wishes? Yes or No

# **APPENDIX 5: THE IOWA MODEL**



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