The Impact of Affect on Intent to Register as an Organ Donor in Mature Adults

Interdisciplinary Medical Sciences Capstone Report

Florida State University College of Medicine
Abstract

The impact of affect on organ donor intent has been suggested in previous research and was investigated in the present study. An online survey was administered, via email, to mature adults to collect information about demographics, exposure, and attitudes towards the topic of organ donation. A two-part survey design was used with standardized pre-test and post-test questions to measure changes in attitudes in response to a combination of educational and affective material. A comparison of the pre-test and post-test scores showed an increase of 8.10% in positive attitudes towards the topic of organ donation. Exposure to a combination of educational and affective material had a positive effect on attitudes towards the topic of organ donation in a majority of mature adults.

Keywords: affect, posthumous, attitude, behavior, intent, organ donor, mature adult, theory of planned behavior
The Impact of Affect on Intent to Register as an Organ Donor in Mature Adults

The United States, and other countries, are currently battling an organ shortage epidemic. The demand for organs is higher than supply and the disparity gap continues to grow each year. The Theory of Planned Behavior (TPB) model has been shown to be an effective tool for determining organ donor behavior, predicted by intent. Previous research has focused on various aspects of the TPB and has attempted to expand the model to include factors that will improve the predictive validity. Many studies have suggested that the inclusion of emotion, or affect, in efforts to recruit organ donors may prove effective: however, little research has been done in this area to date. The purpose of the current study is to determine the impact that affect (emotion) has on attitudes towards the topic of organ donation in mature adults.

Review of Literature

The current organ shortage, or lack of organs available for procurement, is a global problem. (Ghaffari et al., 2018) Worldwide, the demand for organs exceeds the supply. (Wakefield, Reid, & Homewood, 2011) In the United Kingdom and Ireland, registered organ donors make up only one third of the population. Government initiatives were put in place in an attempt to increase organ donor registration rates with no noticeable effect as of 2015. (Ghaffari et al., 2018) Organ donor registration rates in Australia are the lowest in the world, placing patients in organ failure at increased risk of death with limited hope for a cure. (Hyde & White, 2009) In other countries, such as Qatar, the organ shortage has gone unchecked until now with an organ donation system in the early stages of development. (Singh, Agarwal, Al-Thani, Al Maslamani, & El-Menyar, 2018)

Although many countries are more greatly impacted by the organ shortage, the United States is by no means exempt. As of January 25th, 2019, the United Network for Organ Sharing
website reported that 113,719 people are currently in need of an organ transplant, 74,421 of which are active waiting list candidates. ("UNOS," n.d.) An estimated 22 people die each day due to organ failure meaning that 5-7% of people currently on the waiting list will die before receiving a life-saving transplant. (Ladin, 2016; Ghaffari et al., 2018) These exceedingly high numbers are the result of a national discrepancy between support for organ donation, and actual organ donor registration rates. (Sukalla, Wagner, & Rackow, 2017) A majority of Americans report highly favorable attitudes towards organ donation. (Quick, Anker, Feeley, & Morgan, 2016a) The National Survey of Organ Donation Attitudes and Behaviors is a tool that has been used over the years to measure national attitudes towards organ donation. In 1993, 93.5% of American adults reported favorable attitudes towards organ donation. Over the years, this number has increased with a 94.9% approval rate reported in 2012. (Ladin, 2016) While over 90% of American adults reported supporting organ donation, only half of the population had actually registered to donate their organs. Between the years of 2005 and 2012, organ donor registration rates increased from 51.3% to 60.1% of the national population. (Ladin, 2016) While this increase in organ donor registration rates is promising, there is still a large gap between support for organ donation and actual action regarding registration. This phenomenon has previously been deemed the “attitude-registration discrepancy”. (Quick et al., 2016a) The organ shortage itself is a danger to the general population, as anyone may fall victim to organ failure at some point in their life. This problem, however, exerts a more devastating effect on certain demographics. Racial and ethnic minorities in the U.S. are less likely to receive organ transplants than their white counterparts due to underrepresentation on state donor registries and overrepresentation on the national transplant waiting list. (Purnell et al., 2013) The organ shortage has also disproportionately impacted older populations, who make up a majority of the
transplant waiting list. (Quick et al., 2016a) The worldwide 5-year survival rate for organ donor recipients is 70% with improvements observed each year. (Doherty, Dolan, Flynn, O’Carroll, & Doyle, 2017) This means, that by increasing the organ donor pool, patients in organ failure have a significantly better chance at survival, and a fulfilling life, post-transplant. Sadly, due to the nature of organ failure, treatment for this condition relies on voluntary donation; either living or post-mortem (posthumous). (Ladin, 2016) An important statistic to note is that, of non-registered participants surveyed, 36.8% said they had reservations regarding organ donation, while 59.2% stated they were open to considering donation. (Ladin, 2016) The gap between support for, and commitment to, organ donation means that future strategies for increasing the donor pool should be geared towards encouraging decision making and increasing donor action in previously unregistered populations. (Ladin, 2016) Research into potential strategies has been a recent focus in global medical, political, and social efforts. (Doherty et al., 2017)

In order to develop strategies effective at increasing organ donor registration rates in the American population, the process of organ donation must first be understood. There are several types of organ donation that take place in the United States, two of which are ‘living’ and ‘deceased’ organ donation. To avoid any negative emotion associated to the word ‘deceased’, this type of donation will henceforth be referred to as posthumous. Posthumous can be used to represent something that occurs or continues after one’s death. (“Posthumous,” n.d.) These types of donations occur via two very different process. This research will focus on posthumous organ donation and, from this point forward, the term ‘organ donation’ will refer to only this specific category. Even though the United States is impacted by the organ shortage, the system that the U.S. uses serves as a model for transplant systems around the world and is considered one of the most effective methods to date. (“UNOS,” n.d.) The United States is an “opt-in” system, which
means organs are not removed unless the individual has decided to register as an organ donor. (Zambrano, 2017) The Organ Procurement and Transplantation Network (OPTN) was established in 1984 after the U.S. Congress passed the National Organ Transplant Act in response to the nation’s organ shortage. The OPTN is operated by the United Network for Organ Sharing (UNOS) under contract with the U.S. Department of Health and Human Services and works to connect all professionals involved in the United States donation and transplantation system. (“Organ Procurement and Transplantation Network,” n.d.) The organ matching process is a collaboration between UNOS’s OPTN and state organ donor registries. When a patient presents with organ failure, a specific procedure is followed to give them the best chance at obtaining the life-saving organ they need. The process is as follows: The patient undergoes extensive testing at a local evaluation center. If they are determined to be a good candidate for transplantation, they are placed on the national transplant waiting list. On the donation end, when an individual dies and meets all the requirements for organ donation, the hospital contacts a local Organ Procurement Organization (OPO). Because there is no national donor registry in the United States, and because policies regarding consent differ from state to state, the OPO manages the organ recovery process. (Rocheleau, 2013) They first check to see if the person is listed in their state donor registry. If the person is registered, the family is notified. If the person is not registered, the family is usually asked for authorization to procure the organs. Upon approval from a local OPO, a medical exam is performed to check the eligibility of the organs for procurement. If the organs are determined to be viable, the OPO gets in touch with the national transplant waiting list and a search for the best recipient ensues. Appropriate matches are determined based on a variety of criteria including blood type, body size, severity of the
patient’s condition, distance between donor and recipient, patient waiting time, and patient availability. (“Organ Procurement and Transplantation Network,” n.d.)

Although the United States boasts a streamlined donor-recipient matching process, potential organ procurement rates are not what they could be. Already low “opt-in” donor registration rates are confounded by secondary factors such as family veto. Family veto is the idea that the family reserves the right to a final say regarding the procurement and donation of their loved one’s organs despite previous organ donor registration. Many states utilize a first-person consent donor registry which allows the individual to consent to organ donation prior to death and removes the burden of decision making from their family. Previously, consent was obtained from next-of-kin postmortem. Even if the individual is not registered as an organ donor, the family is typically approached and asked if they wish to donate the viable organs. (Zambrano, 2017) Family refusal to consent to organ donation is a major contributor to the organ shortage in the United States. (Siminoff, Marshall, Dumenci, Bowen, Swaminathan, & Gordon, 2009) For this reason, the U.S. is referred to as an “imperfect opt-in system”. (Zambrano, 2017) Low organ procurement rates are often attributed to a failure of the individual to communicate their desires for organ donation to their family. (Hyde & White, 2009) A common criticism of family veto is that when a family decides not to procure a donor’s organs, they fail to honor the wishes of their family member. (Zambrano, 2017) This is not actually the case. As the system is currently set up, registration as an organ donor is a decision of consent and not a legally binding document. (Quick et al., 2016a) This means that foregoing the use of a donor’s organs is not a legal violation of their wishes unless explicitly stated otherwise in more formal documentation. (Quick et al., 2016a) The main problem with family veto is that too many organs are then not removed because of family wishes. (Zambrano, 2017) Previous research has been done on the
effectiveness of organ procurement coordinators. Organ procurement coordinators are the individuals responsible for interacting with the family during a time of loss and engaging with them in conversations regarding organ procurement and donation. Organ procurement coordinators are considered the most effective method of obtaining consent from families. Highly trained coordinators are comfortable speaking to families about donation and answering donation related questions. (Siminoff et al., 2009) A study done by Siminoff et al. showed that time spent talking to families, and number of organ donation-related topics discussed, were both correlated with an increase in consent rates from 46.3% to 55.5%. Because family veto is a major obstacle to organ procurement, recent research has focused on how to effectively facilitate donor communication with family members regarding their organ procurement wishes.

Although family veto is responsible for a majority of previously designated organs not being procured, the source of the organ shortage in the United States is multifaceted. Attitudes toward organ donation are associated with a wide range of variables including secular and religious beliefs, fear, misconceptions, and anxiety about bodily integrity and medical mistrust. (Wilczek-Ruzyczka, Milianiak, Przbylowski, Wierzbicki, & Sadowski, 2014) Attitudes, however, are the most significant predictors of engaging in a behavior, specifically organ donor registration. (Conner, Sheeran, Godin, & Germain, 2013) Because of this, it is important to understand the positive and negative attitudes that individuals have towards organ donation. An underlying theme of many negative attitudes is a lack of knowledge about organ donation.

Reluctance to donate generally stems from lack of knowledge regarding what it means to be an organ donor. (Sukalla et al., 2017) A survey published in 2011 showed that United States citizens exhibit poor knowledge in religious support for organ donation, concept of brain death, and beliefs regarding requirements for organ donor registration. (O’Carroll, Foster, McGeechan,
Lack of knowledge not only impacts registration action, but also the ability of people to comfortably discuss their decisions with family members, who will ultimately decide whether or not organs are procured. Many people feel they are incapable of talking about or defending their decision to become an organ donor because they don’t have the necessary facts or are unsure how to bring up the conversation with their friends or loved ones. (Hyde & White, 2009) Previous research has shown that individuals most likely to have positive attitudes towards donor registration are those that possess more knowledge about organ donation. (Wakefield et al., 2011) A study conducted on students showed that knowledge and attitudes regarding donation improved after educational programs designed to promote donor registration. (Ghaffari et al., 2018) Since anxiety is a fear of the unknown, information should relieve people’s fears about donation. (Sukalla et al., 2017) Proposed resolutions to the organ shortage, thus far, have included educational campaigns aimed at increasing the knowledge of the general public about the topic of organ donation. (Wakefield et al., 2011) The organization, Donate Life America, created an optimal registry system to increase public awareness of the need for organ donation through education and intervention. (Patel et al., 2016) Some experts have suggested that health care providers take on the responsibility of educating their patients about the importance of organ donor registration. These experts have indicated that family physicians are in a unique position to have an impact on organ donor registration rates because they can work with patients, over an extended period of time, to educate them and talk through options regarding posthumous donation. (Ladin, 2016) A new Centers for Medicare and Medicaid Services (CMS) policy began to reimburse physicians for end-of-life discussions in January of 2016 meaning that physicians can now be reimbursed for these organ donor registration discussions with their patients. (Ladin, 2016)
Because of the national and global threat imposed by the organ shortage, a lot of research has been done on the factors that influence individual decisions to register as an organ donor. Research has found that organ donation is often viewed as a “second-hand reality” via entertainment and news because most people aren’t personally affected by organ donation. (Reynolds-Tylus & Quick, 2017) This means that most individuals believe that the organ shortage will not impact them, and that they have no responsibility to contribute to a resolution. Frequent inaccuracies in media portrayals also contribute to hesitancy regarding organ donor registration. (Reynolds-Tylus & Quick, 2017) The amount of misinformation circulating through the general public regarding organ donation is overwhelming. Additional factors such as perceived societal norms influence individuals at time of registration. Because most organ donor registration occurs at the Department of Motor Vehicles (DMV) when obtaining a driver’s license, the DMV has been the focus of understanding potential donor mentality and what factors facilitate the donor decision making process. (Patel et al., 2016) Surprisingly, DMV clerks have been found to have the lowest organ donor registration rates recorded. (Patel et al., 2016)

Inaccurate media portrayals of organ donation, and interaction with populations that don’t necessarily support registration may inspire fear in individuals that would otherwise consent to donation. Fear of health-related behaviors, such as attending doctor appointments and receiving surgery, is a major predictor of willingness to engage in particular actions, and as such, it is a major obstacle to donor registration. (Wagner & Manolis, 2012; O’Carroll et al., 2011) The topic of organ donation also tends to stir up a sense of existential anxiety stemming from a fear of mortality. (Wagner & Manolis, 2012) The fear of death and the anxiety associated with mortality have severely impacted organ donor registration rates. (Wagner & Manolis, 2012) Unfortunately, a lot of these fears are unfounded.
Some of the most influential negative attitudes towards organ donation have been collectively studied and deemed “non-cognitive factors”. These non-cognitive factors include, but are not limited to: ick factor, bodily integrity, jinx factor, and medical mistrust (defined below). (Reynolds-Tylus & Quick, 2017) One study found medical mistrust and jinx factor to be the most influential predictors of organ donor registration compared to other variables. (Reynolds-Tylus & Quick, 2017) Another study stated that non-cognitive factors are better predictors of organ donor status than individual organ donation knowledge. (Quick, Reynolds-Tylus, Fico, & Feeley, 2016b) Other studies, however, have found differing results. The most reasonable conclusion is that each non-cognitive factor is important and has the ability to individually influence potential donors. One constant result, however, is that non-registered donors typically reported higher rates of non-cognitive factors than registered individuals. (Quick et al., 2016b) Ick factor has been described as a basic disgust reaction. Disgust is a factor in avoidance or delayed behavior, especially in regard to organ donation. Disgust is also correlated with negative attitude which is, in turn, correlated with low intent to donate. There are individual differences in disgust sensitivity, so everyone is impacted differently by the ick factor and studies aimed at only reducing this aspect of misinformation cannot be considered comprehensive. Bodily integrity is a belief in the need to maintain the body, as it originally was, after death and often stems from misguided religious beliefs. Jinx factor is a superstitious belief or fear that signing up to be a donor prematurely brings about death. Medical mistrust, the final non-cognitive factor, is a common fear that doctors do not provide adequate care to organ donors and even seek to bring about premature death in order to procure viable organs. (O’Carroll et al., 2011) One study provided evidence that registered and non-registered organ donors receive similar levels of critical care. The study even went so far as to suggest that organ donors may
receive better and more aggressive care than non-donors. An additional study of physicians and organ donor registration rates showed that physician registration rates were high compared to the national average, suggesting that lack of care for registered organ donors is not likely. When informed of these results, willingness to donate increased four-fold in previously unregistered individuals. (Patel et al., 2016) In order to combat misinformation and increase organ donor registration, refutational messages should be developed to educate against commonly held misbeliefs. (O’Carroll et al., 2011)

As previously stated, non-cognitive factors have the potential to differentially influence individuals and should be considered as a collective whole. That being said, some non-cognitive factors have been shown to have more profound impacts on specific racial and ethnic minority groups in the United States. (Purnell et al., 2013) African Americans and Hispanics, when surveyed, were significantly less likely to trust physicians than their white counterparts. (Purnell et al., 2013) African Americans and Hispanics were also more likely to disagree with organ donation due to religious affiliations and a belief in bodily integrity. (Purnell et al., 2013) Bodily integrity and jinx factor generally affected Caucasians less than their African American and Hispanic counterparts. (Reynolds-Tylus & Quick, 2017) Future organ donor advocates must be aware of racial and ethnic differences in predictors of registration intent in order to tailor messages to specific populations to promote organ donor registration rates. (Reynolds-Tylus & Quick, 2017)

Religious affiliations, as mentioned earlier, are often considered a facet of bodily integrity. Many individuals believe that it is against their religious beliefs to alter the integrity of their body and claim to fear repercussions in the afterlife. The results of one survey reported that Buddhist and Islamic religious affiliations tended to hold more negative attitudes towards organ
donation than their non-religious or Christian counterparts. (Wakefield et al., 2011) These beliefs, however, are misinformed as all major religions have issued statements supporting organ donation. If direct support for organ donation has not been expressed by religious leaders, other statements have been issued affirming that the decision is up to the individual and that the action of donating one’s organs is not condemned in scripture. (O’Carroll et al., 2011) To ensure that religious misbeliefs are not impacting the registration rates of potential donors, future organ donor advocates must be able to engage with the general public and correct any religious misperceptions that could be acting as barriers to registration.

Low registration rates, family veto, lack of knowledge, misinformation, societal influence, fear, non-cognitive factors, cultural, and religious beliefs all have negative impacts on the organ shortage. In order to reverse the organ shortage epidemic, researchers have put a focus on understanding what factors contribute to increasing organ donor registration rates. The Theory of Reasoned Action (TRA) was introduced, and findings from the use of this model suggested that attitudes and subjective norms predict intentions which, in turn, influence behavior. (Ghaffari et al., 2018) Another model, which builds upon TRA, was introduced and incorporated a third construct; perceived behavioral control. (Hyde & White, 2009) This new model is the Theory of Planned Behavior (TPB) and was originally proposed by researchers Ajzen and Fishbein. It is one of the most commonly used behavior change theories shown to have a significant impact on increasing target behavior. (Ghaffari et al., 2018) The first construct of TPB is attitude, which can be defined as an individual’s evaluation of a behavior, or the way they feel about something, either positive or negative. (Conner et al., 2013; Hyde & White, 2009) In terms of organ donation, this can be viewed as the perceived effectiveness or anticipated outcome of registering to be an organ donor. (Ghaffari et al., 2018) The second construct of TPB
is subjective norms. Subjective norms are the perceived social pressure to engage in a specific behavior. (Hyde & White, 2009) The third, and final, construct of TPB is perceived behavioral control. This construct measures the perceived amount of control and confidence an individual has in performing a target behavior. (Conner et al., 2013) Some of the original research done using the TPB, within the context of organ donor registration, found that attitude toward organ donation was the most consistent determinant of intention to register. (Powpaka, 1996) Other research, done by Hubner and Kaiser (2006), found that attitude, subjective norms, and perceived behavior control were all significant predictors of individual intent to register. These findings lined up with the main idea behind TPB which states that intentions determine behavior and intentions arise from attitudes, subjective norms, and perceived behavioral control. (Hyde, Knowles, & White, 2013) In terms of organ donation, this main idea suggests that donor registration behavior will be adopted if an individual has the intent to engage in that behavior. (Ghaffari et al., 2018) Not only do these intentions predict behavior in the moment, they have also been shown to reliably predict individual donation-related behaviors up to 2 months later. (Rocheleau, 2013) Since these initial findings, studies have looked at the effectiveness of TPB compared to other predictive models. In 2009, Hyde and White found that TPB accounted for a 39% variance in intentions and a 27% variance in behavior. Similar research, repeated in 2013 by Hyde et al., found that TPB accounted for a 39% variance in intentions and a 37% variance in behavior. Based on these findings, TPB was confirmed to be an effective model to predict behavior, specifically in terms of organ donation. (Ghaffari et al., 2018; Rocheleau, 2013) All of this knowledge and research led to the use of the TPB framework in developing interventions related to organ donor registration. These interventions were designed to target the constructs within TPB and promote behavior change.
The need to increase the posthumous organ donor pool has led researchers to look at ways of improving upon the traditional TPB. (Rocheleau, 2013) The strength of the TPB is in its simplicity. This simplicity, however, may also lead to the neglect of other important domain-specific predictors of behavior. (Rocheleau, 2013) The idea of an extended TPB was introduced with the hope that incorporating additional factors, related to intentions, could increase the predictive validity of the model. (Rocheleau, 2013; Hyde & White, 2009) Since this introduction, organ donation intentions and behaviors have been studied using both the traditional and extended TPB. (Rocheleau, 2013) Research using an extended TPB has shown that the inclusion of additional variables such as moral norms and anticipated regret have improved the capacity of TPB to predict intentions and behaviors (Hyde et al., 2013; O’Carroll et al., 2011)

One flaw in the TPB, and its current extended models, is the firm foundation in cognitive influence. (Conner et al., 2013) The classical and extended TPB models have not explicitly focused on affect, which previous research has highlighted as a potential flaw. The failure to account for the role that this emotional construct plays in decision making could be resulting in a less than optimal impact on increased donor registration behavior. (Rocheleau, 2013; Conner et al., 2013) Affective attitudes are those related to feelings and emotions and have shown to be stronger predictors of intentions than cognitive attitudes. (Doherty et al., 2017; Conner et al., 2013) Individual affective reactions towards donation should therefore be assessed when accounting for individual intention to engage in donation related behaviors. (Rocheleau, 2013) Affect is generally classified into anticipatory and anticipated affect. Anticipatory affect is defined as the affect experienced in the moment while participating in a behavior. Anticipated affect is defined as the affect one expects to feel after engaging in a behavior. (Rocheleau, 2013) Most of the previous research done using an extended TPB model has focused on anticipated
affect using the constructs of moral norms and anticipated regret. This research has shown that inclusion of anticipated affect in the TPB model improves explanatory and predictive ability. (Rocheleau, 2013) Little to no research has been done on the impact of anticipatory affect on improving attitudes towards organ donation and, in turn, intent to register as an organ donor. Education is a factor known to have a positive impact on donation and transplant rates, however, the effect of simultaneous cognitive (educational) influence and anticipatory affect has not been studied. (Wilczek-Ruzyczka et al. 2014; Conner et al., 2013) This integrative approach has been suggested in previous literature and is the focus of the current study. (Wilczek-Ruzyczka et al. 2014)

**Methods**

The purpose of this study was to determine the impact that affect has on attitudes towards the topic of organ donation in mature adults. A survey was designed to incorporate basic demographic and exposure questions as well as pre-test and post-test questions to measure the impact that a combination of educational and emotional video material had on attitudes towards the topic of organ donation. The impact of affect was measured by comparing pre-and post-test data.

**Sample**

Participants were recruited through email distribution of a Qualtrics survey. A total of 39 people completed the survey within the 5 days it was available. Of the responses submitted, 21 respondents fit the requirements for the target population. Data filtering was used so that only the responses from individuals meeting the requirements for the target population were used. The target population was mature adults, age 50-64. Mature adults were used, rather than a convenience sample of college undergraduates, because they make up around 19% of the U.S.
population. Mature adults are also an ideal sample because they make up a high percentage of those awaiting organ transplants while also being underrepresented on state organ donor registries. (Quick et al., 2016a; Quick et al., 2016b) Age myth is a major contributor to lower than average donor registration rates in mature adults and is defined as the belief that, at a certain age, organs are no longer viable for transplantation. This common misperception is a major barrier to organ donation among mature adults. (Quick et al., 2016b) Support for organ donation has also been observed to decrease among those age 66 and older. This means that mature adults are a prime target audience for attitude and behavioral change strategies. (Ladin, 2016) Mortality rates also spike at age 50 making mature adults the biggest pool of potential donors. Little research has been done on mature adults in terms of organ donation despite these important demographic factors. (Quick et al., 2016a) Out of the 21 participants that met the requirements for target population; 57% were female and 43% were male. 90% identified as White/Caucasian and 10% identified as Asian, 81% were already registered organ donors, 14% were not, and 5% were unsure of their organ donor status.

**Materials**

Participants were provided with a document that outlined the purpose and risks of the study (see Appendix A). Before the survey took place, participants were informed that their anonymous results would be presented, as part of a statistical whole, at a research symposium at the end of the academic semester. The principal investigator developed the survey questions based on previous research done in the field of organ donation and carefully screened the questions for bias and to ensure that measurements gathered would be relevant to the proposed question of interest (see appendix B). While studying organ donor registration material, Doherty et al. (2017) found that omitting certain attitudinal items from donor intent surveys had a
statistically significant impact on donor registration rates. This study suggested that attitudinal questions have the potential to prime respondents and offer contextual cues that have been shown to negatively influence the question responses provided by research participants. (Doherty et al., 2017) Based on these findings, the wording of attitudinal questions included in the present study were carefully considered. An online survey site, Qualtrics, was used to collect and record data. The survey consisted of 4 demographics questions, 8 exposure questions, a pre-test containing 7 questions, two free-use videos, and a post-test containing the same 7 questions as the pre-test. All pre-test and post-test responses were measured on an 11-point Likert scale (0 - strongly disagree, 5 - neutral, and 10 - strongly agree). Wording of the questions was formatted so that higher numbers represented more positive attitudes towards the topic of organ donation.

**Procedures**

Participants were informed, prior to survey administration, of the risks associated with participating in the study and their ability to withdraw at any time without penalty. Participants were informed that all answers would remain anonymous and that their participation in the survey would remain confidential. Participants were not given any prior indication regarding the specific intent of the study to avoid biased results. Participants were, however, informed of the general topic for disclosure purposes. All participants were contacted via email with the same message and public survey link (See Appendix C). For consistency, all participants were administered the same set of questions and supplemental material in the exact same order and format.

**Results**

Observational findings were used to report the results of the present study because the sample size was too small to provide any statistical significance for the results. In order to
determine the impact of affect on attitude toward the topic of organ donation in mature adults, pre-test and post-test scores were compared. Pre-test scores showed existing attitudes without influence from affective material. Post-test scores showed the influence affective material had on existing attitudes towards organ donation. If all 21 survey participants had answered all 7 pre-test questions with the maximum score of 10 points on the 11-point Likert scale (0 – strongly disagree, 5 – neutral, 10 – strongly agree), the total score would have been 1470. The actual pre-test total score for the entire survey population was 1235 (Figure 1). This data suggests that 84.01% of pre-test responses were correlated with positive attitudes towards the topic of organ donation before exposure to affective material. The post-test score reported for the entire survey population was 1354 (Figure 2). This change from pre-test to post-test scores after exposure to affective material is associated with an increase in positive attitude from 84.01% of responses to 92.11%. Interestingly, all survey participants, except 2, showed an average increase from pre-test to post-test score of 6.47. The two participants that did not show an increase actually showed a 2-point decrease after exposure to affective material. These anomalies could be explained by exposure to priming attitudinal questions as suggested by Doherty et al. in their 2017 study.

![Overall Pre-test Responses](image)

Figure 1. Survey participant pre-test score distribution.
After a general analysis was done, demographics were analyzed for patterns in survey response. Gender was the only demographic with enough response distribution to validate an analysis. Due to the different number of male and female participants, the differences in gender responses could not be directly compared. Instead, response ratings were analyzed as percentages of the statistical whole for each gender. The percentage results for the individual gender analyses were then compared.

If all 9 male respondents had answered all 7 pre-test questions with the maximum score of 10 points on the 11-point Likert scale (0 – strongly disagree, 5 – neutral, 10 – strongly agree), the total score for the male demographic would have been 630. The actual pre-test total score reported for the male demographic was 529 (Figure 3). This data suggests that 83.97% of male pre-test responses were correlated with positive attitudes towards the topic of organ donation before exposure to affective material. The post-test score reported for the male demographic was 581 (Figure 4). This change from male pre-test to post-test scores after exposure to affective material is associated with an increase in positive attitude from 83.97% of male responses to 92.22%.

Figure 2. Survey participant post-test response distribution.
If all 12 female respondents had answered all 7 pre-test questions with the maximum score of 10 points on the 11-point Likert scale (0 – strongly disagree, 5 – neutral, 10 – strongly agree), the total score for the male demographic would have been 840. The actual pre-test total score reported for the female demographic was 710 (Figure 5). This data suggests that 84.52% of female pre-test responses were correlated with positive attitudes towards the topic of organ donation before exposure to affective material. The post-test score reported for the female demographic was 768 (Figure 6). This change from female pre-test to post-test scores after
exposure to affective material is associated with an increase in positive attitude from 84.52% of female responses to 91.43%.

**Discussion**

The goal of the present study was to determine the impact of affect on intent to register as an organ donor in mature adults. To evaluate this potential impact, an anonymous survey was administered, via email, to mature adults and results were collected. The survey was designed to incorporate basic demographic and exposure questions as well as pre-test and post-test questions
to measure the impact that a combination of educational and affective material have on attitudes towards the topic of organ donation.

Most of the prior research done on increasing organ donor registration has focused on reducing the negative effects of family veto, lack of knowledge, misinformation, societal influence, fear, non-cognitive factors, cultural, and religious beliefs. Other research has gone into developing and testing the best predictive models for improving registration related behaviors. Over time, the Theory of Planned Behavior (TPB) has risen to the top. (Ghaffari et al., 2018) Despite the promising results of this model, the simplicity of its three constructs, attitude, subjective norms, and perceived behavioral control, have posed as barriers to its further success. (Rocheleau, 2013) Additional constructs have been added to improve the predictive validity, resulting in an extended model. One construct, suggested in previous research, is affect and is the topic of the present study. (Wilczek-Ruzyczka et al. 2014)

Results from the present study showed that, when exposed to affective material, an average increase of 8.10% was observed from pre-test to post-test scores. These higher post-test scores are correlated with more positive attitudes towards the topic of organ donation. These results suggest that exposure to affective material directly, and positively, influences the attitudes that mature adults hold towards the topic of organ donation. Some individual responses showed a decrease in overall attitude toward the topic of organ donation, but these anomalies were accounted for through comparisons to results discussed in previous research. The gender demographic was then analyzed to determine if affective material differentially effects male and female responses. No significant differences were found between the genders and affective material can be expected to influence both genders at a comparable level. One interesting finding was that statement 6, on both pre-test and post-test responses, received the lowest overall
score. The question stated: “I feel it is important for me to discuss the topic of organ donation with individuals outside my immediate family.” The lower than average scores observed for this statement suggest that survey participants do not feel the need to discuss the topic of organ donation with individuals outside their immediate family. This finding is concerning because previous research has suggested that willingness to discuss the topic of organ donation is correlated with willingness to engage in donation related behaviors. (Hyde & White, 2009)

There were several limitations that impacted the present study. The sample population was limited to mature adults (age 50-64) and results can, therefore, only be generalized to this small demographic. The impact of affect on other age groups cannot be determined from the results obtained in this study. The lack of diversity recorded for other demographics such as race/ethnicity, education level, and current organ donor status did not allow for additional analysis. More distribution within these demographics could have provided interesting implications for the future direction of this research. The nature of the present study could also be viewed as a limitation. The survey responses were solely dependent on self-reported data, may have been idealized, and may not have accurately represented the individuals’ attitudes towards the topic of organ donation. There was also no control group included in this study.

In conclusion, general analysis suggests that affective material has a positive influence on attitudes towards the topic of organ donation in mature adults. Attitudes towards organ donation have been strongly associated with registration intentions in previous research. (Powpaka, 1996) The TPB also states that intent determines behavior. (Hyde, Knowles, & White, 2013) The findings from the present study along with the association between attitude, intent, and behavior suggest that incorporating affective material into strategies aimed at increasing organ donor registration would be beneficial.
To improve upon the findings of the present study, future research should aim to increase study population size and diversity. An increased population size would allow for more significant statistical analysis and increase the likelihood that results could be generalized to the entire population of the United States. Increased diversity would allow researchers to look at variations in response to affective material across populations. Different populations and demographics may respond more favorably to affective material than others. These findings could then allow registration strategies to be tailored to specific populations or demographics. A control group should also be included in future research to distinguish between the impact of a combined educational and affective model and the impact of solely educational model. Lastly, future research should focus on ways to increase early educational and affective exposure to the topic of organ donation. This early exposure will help to normalize the topic of organ donation and increase conversation. Increased conversation will, in turn, increase population willingness to engage in organ donor registration behavior. This willingness to engage in donor registration behavior will begin to resolve the organ shortage epidemic in the United States.
References


Hyde, M. K., & White, K. M. (2009). To Be a Donor or Not to Be? Applying an Extended Theory of Planned Behavior to Predict Posthumous Organ Donation Intentions. *Journal of


Appendix A

Purpose and Risks Document

The Impact of Affect on Intent to Register as an Organ Donor in Mature Adults

**PRINCIPAL INVESTIGATOR**
Samantha King
Undergraduate Student, Florida State University
slk15b@my.fsu.edu

**PURPOSE OF STUDY**
1. To collect information regarding the knowledge and attitudes of mature adults about the topic of organ donation

**STUDY PROCEDURES**
1. You will be asked questions about your demographics and current attitudes/intentions regarding organ donation.
2. You will be asked to read/watch a brief excerpt/video containing information about a patient’s experience receiving an organ.
3. You will be asked follow-up questions regarding any changes in attitudes and intentions towards organ donation as well as questions about your opinions on the informational material.
4. The survey will take approximately 15 minutes.

**CONFIDENTIALITY**
Findings will be presented in a poster format at a symposium as an educational exercise to satisfy a course requirement for the Interdisciplinary Medical Sciences Bachelor of Science Degree.

This study will not be published or submitted to a journal.

Your responses during the interview will be anonymous. Every effort will be made to preserve your confidentiality.

Participant data will be kept confidential except in cases where the researcher is legally obligated to report specific incidents. These incidents include, but may not be limited to, incidents of abuse and suicide risk.

**VOLUNTARY PARTICIPATION**
Your participation in this study is voluntary. You are free to withdraw at any time.

Thank you in advance.
Appendix B

Survey

**Demographics:**

Q. 1 Gender
Male
Female
Do not wish to answer

Q. 2 Age
Under 50 years old
50-64 years old
65+ years old
Do not wish to answer

Q. 3 Ethnicity
White
Hispanic or Latino
Black or African American
American Indian or Alaska Native
Asian
Native Hawaiian or Pacific Islander
Other

Q. 4 Education
High school graduate, diploma or the equivalent (ex: GED)
Some college credit, no degree
Trade/technical/vocational training
Associate degree
Bachelor’s degree
Master’s degree
Professional degree
Doctorate degree
Other
Exposure:
Q. 1 Are you a registered organ donor?
Yes
No
Not Sure

Q. 2 Have you heard the term ‘organ donation’?
Yes
No

Q. 3 How did you first hear about organ donation?
Word of mouth
Newspaper
Television
Organ Donor Organization
DMV (Department of Motor Vehicles)
Other (please specify)
I have not previously heard the term ‘organ donation’

Q. 4 Have you heard about donation of the kidney?
Yes
No

Q. 5 Have you heard about donation of blood?
Yes
No

Q. 6 Have you heard about donation of the heart?
Yes
No

Q. 7 Have you heard about donation of the liver?
Yes
No

Q. 8 Have you heard about donation of the cornea?
Yes
No
Pretest:
On a scale of 0-10, please mark the answers below that best indicate your feelings towards the statements given: (0 – strongly disagree, 5 – neutral, 10 – strongly agree)

Q. 1 I feel informed about the topic of organ donation.
Q. 2 I support the donation of organs for transplant.
Q. 3 I feel it is important to register as an organ donor.
Q. 4 As next of kin, I would be willing to donate the organs of a loved one for transplant.
Q. 5 I feel it is important for me to discuss my wishes regarding organ donation with my immediate family.
Q. 6 I feel it is important for me to discuss the topic of organ donation with individuals outside my immediate family.
Q. 7 I feel that organ donation allows something positive to come out of a person’s death.

Videos:
Please watch the following videos in order and in their entirety:
https://www.youtube.com/watch?v=HuKx2a5HkIM
https://www.youtube.com/watch?v=LZxUKNtV3Xo

Post-test:
On a scale of 0-10, please mark the answers below that best indicate your feelings towards the statements given: (0 – strongly disagree, 5 – neutral, 10 – strongly agree)

Q. 1 I feel informed about the topic of organ donation.
Q. 2 I support the donation of organs for transplant.
Q. 3 I feel it is important to register as an organ donor.
Q. 4 As next of kin, I would be willing to donate the organs of a loved one for transplant.
Q. 5 I feel it is important for me to discuss my wishes regarding organ donation with my immediate family.
Q. 6 I feel it is important for me to discuss the topic of organ donation with individuals outside my immediate family.
Q. 7 I feel that organ donation allows something positive to come out of a person’s death.
Hello,

My name is Samantha King and I am a Senior at Florida State University. I will be graduating this May from the Interdisciplinary Medical Sciences Degree Program with a major in Clinical Professions. One of the graduation requirements for my major is a research project and I have chosen organ donation as my topic. In order to make my research more meaningful, I have decided to conduct a survey and present my findings as part of a research symposium at the end of the semester. I would really appreciate it if you could take no more than 15 minutes to complete the survey linked below. This survey time includes two brief videos.

[Click Here to Launch Survey]

I have attached a document outlining the Florida State University guidelines regarding surveys. I encourage you to reach out with any questions. All answers will be anonymous.

Thank you in advance,

Samantha King
E-mail: slk15b@my.fsu.edu