

EARLY IDENTIFICATION OF THE NON-DIRECTED KIDNEY DONOR:
ARE THERE PERSONAL CHARACTERISTICS OF COLLEGE STUDENTS
THAT CAN PREDICT THEIR WILLINGNESS TO CONSIDER NON-DIRECTED
KIDNEY DONATION?

by

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ABSTRACT

There is an escalating gap between those patients with End-Stage Renal Disease [ESRD] and available kidneys. A reasonably new and untapped resource of potential kidneys is the non-directed kidney donor. College students are in the infantile stages of their adult identity development and if students who are willing to consider non-directed donation [NDD] can be identified, educational interventions may be created to nurture this interest and increase the likelihood they will donate at some time in their lives. This study attempted to determine if there are characteristics of college students that make them willing to consider non-directed donation. Four hundred and fifty eight students completed a 39-question survey. A structural equation model was created to identify predictors of college students' willingness to consider NDD. The model had four moderating variables, Sex/Gender; Race/Ethnicity; Religion; and Sexual Orientation; two mediating variables, Political Ideology and Religiosity; and three latent variables, Experience with Kidney Disease, Donation, and Transplantation; Knowledge on Kidney Disease, Donation, and Transplantation; and Medical Altruism. A binary correlation of variables was run using the SPSS Analysis of Moment Structure AMOS Bootstraps Path Analysis program. Path

coefficients and R^2 (Kenny, 2015) were used to determine the predictive power of the model variables. It was found that very little in the model predicted students' willingness to become NDD. The only variable that showed predictive power was Medical Altruism ($r = .14, p < .01$). Goodness of fit tests were run using the Relative Chi Square (CMIN/DF), Chi Square/Degree of Freedom Ratio and Root Mean Squared Error (RMSE) indices and the original model was not a good fit to the data. As a result, a new model was created to determine predictors of Medical Altruism. It was found that age ($r = .17, p < .01$) and the importance of loved ones' opinions ($r=.11, p=.022$) had some predictive power. Older students and students who made medically altruistic decisions independent of the approval of others were more likely to be medically altruistic and Medical Altruism was a predictor of willingness to consider NDD. Future research should work to identify both independent and altruistic college students. Once identified, educational interventions can be created to alert them about the kidney shortage and the donation process in an attempt to help increase their preexisting inclination towards donation.

1. INTRODUCTION

The Problem

There is an escalating gap between people with End-Stage Renal Disease [ESRD] awaiting kidney transplants and available kidneys (USRDS, 2014).

Sources of kidneys include deceased donors, people who donate to identified recipients, and non-directed donors [NDD], people who do not specify their recipients (UNOS, n.d.). Non-directed donation is rare and an untapped source of donor kidneys. Lack of education about the need for kidneys and lack of knowledge about the opportunity to donate may be part of the problem.

Identifying likely donors and initiating educational interventions to target likely donors might lessen the gap between those who need kidneys and those who receive them. Therefore, the purpose of this study was to create a donor profile of college students willing to consider non-directed donation by identifying

1. the demographic characteristics of college students willing to consider non-directed donation
2. the personal characteristics that make college students more likely to consider non-directed donation
3. the level of knowledge of kidney disease and donation that make college students more likely to consider non-directed donation
4. the relationships between demographics, knowledge and experience, and medical altruism and the willingness to consider non-directed donation.

Background Information

Chronic kidney disease [CKD] is increasing in the United States. More than 26 million Americans have CKD and there were 47,112 reported deaths in 2013 (CDC, n.d.). End-stage renal disease [ESRD] is the final stage in CKD (Medline Plus, 2014). When the kidneys fail, the patient has one of two treatment options, either to start on renal replacement therapy (dialysis) or to seek a transplant (Abecassis, Bartlett & Collins, 2008; American Kidney Fund, n.d.). It is well established that transplantation is the treatment of choice for ESRD patients. Dialysis is more costly and is less effective, more restrictive, and lowers the quality of life (Berns, Brennan & Sheridan, 2013; Schaubel, Desmeules, Mao, Jeffrey & Fenton, 1995). Kidneys come from both cadaver donations and live donations (USRDS, 2014). Kidneys that come from living donors have better outcomes than do those that come from cadaver donors (Koo, Welsh, McLaren, Roarke & Morris, 1999; Terasaki, Cecka, Gjertson, & Takemoto, 1995).

According to the United States Renal Disease System [USRDS] 2014, in the United States there is an increasing gap between the number of people with ESRD who need kidneys and the number of available kidneys (Ge, Kaczmarczyk, Biller-Adorno, 2014; Oliver, Ahmed & Woywodt, 2012; Pradel, Mullins & Bartlett, 2003). The wait time for a kidney transplant is between 2.5 and 5 years, depending on the blood type (Cecka, 2000; Kranenburg et al., 2008; OPTN, 2012)

and can exceed 10 years (Gill et al., 2005; Ojo et al., 2001). According to the Organ Procurement and Transplant Network [OPTN], in the United States as of August 1, 2015 there are 109,030 people on the waiting list for kidneys.

The United Network for Organ Sharing [UNOS] identifies types of living donors. A live donor can donate with a recipient in mind, most often a family member or friend, or to an unknown anonymous recipient. This type of donor is what is called a non-directed donor (UNOS, 2014). For many years, because of the necessity of being a close genetic match, living kidneys were only transplanted from blood-related family members, but with the advancement in anti-rejection drugs, it is no longer necessary to be a Human Leukocyte Antigen [HLA] match in order to be a suitable kidney donor (Davis & Delmonico, 2005; Gjertson & Cecka, 2000; Voiculescu et al., 2002). As a result, non-directed kidney donors [NDD] can become a viable source of kidneys, but as of yet are an untapped resource. Increasing non-directed donation has great promise for narrowing the gap between those who need kidneys and those who receive them.

Non-directed kidney donation is rare. The first non-directed kidney donations in the United States were recorded in 1998, and by the year 2000 there were only 31 recorded donations (OPTN, n.d.). Within the medical community, this type of donation was initially met with considerable controversy (Henderson

et al., 2003; Mueller, Case & Hook, 2008). The skepticism centered on the question of the mental stability of people who would willingly put themselves in harm's way to donate their kidneys to someone they did not know and would likely never meet (Cecka, 2000; Henderson et al., 2003; Landolt et al., 2001), but research has demonstrated as early as 1971 (Sadler, Davison, Carroll & Kountz) that non-directed donors were as mentally stable as the non-donating public both before and after their donations (Clemens, Thiessen-Philbrook & Parikh, 2006; Kranenburg et al., 2008). Even with the growing acceptance among physicians, there were only 955 NDD in the U.S. between 1999 and 2010 (Brethel-Haurwitz & March, 2014) and another 159 in 2011 (Fussell, 2013).

There is emerging interest in the non-directed kidney donor. Much of the research focuses on identifying the characteristics and background of the NDD (Gilbert, Bingham, Batty & Veatch, 2005; Jacobs, Roman, Garvey, Kahn & Matas, 2004; Mark, Baker, Aguayo & Sorensen, 2006) and discovering what motivates them to donate (Challenor & Watts, 2014; Clarke, Mitchell & Abraham, 2014; Massey et al., 2011). So, the questions become "Why do people donate their kidneys to strangers?" and "Are there identifiable life events or patterns of behavior that lead to them become non-directed organ donors?" Studies show that there is a pattern of altruistic behavior in their past, particularly for the medicinal well-being of strangers such as blood donation (Hyde & White, 2009a;

Jacobs et al., 2004,) and being on the national bone marrow (Mark et al., 2006) and deceased organ donor registries. Hyde and White (2009a) suggest that this relationship be studied further to determine if there is a relationship between willingness to donate a kidney and the number of times a person has donated blood.

Philosophical Framework

It is thought that altruism is learned by doing and that good acts are rewarding in themselves. Andre' and Velasquez (1992) studied blood donation patterns to help understand this form of altruism and address the epistemological question, "How do people learn to give?" They apply Aristotle's reasoning to explain. The first time a person performs an altruistic act they do it as a result of some external pressure or influence. Following the act, they are rewarded by a sense of accomplishment and satisfaction; they feel good about what they have done. The reward is reinforcing enough that it is believed that they are likely to repeat the act and other altruistic behaviors thought to evoke similar feelings. A pattern for altruistic giving is established. As Andre' and Velasquez (1992) suggest, "Donors learn to give by giving". It then seems reasonable to assume that people who have donated blood, and are on the bone marrow and deceased organ donation lists may be potential non-directed donors.

Virtue Ethics is a philosophical framework by which this research is based. Aristotle was one of its early proponents. In its simplest form, Virtue Ethics is based on the principle that people want to do the right thing; they want to be virtuous (Stanford Encyclopedia, 2013) and is a “framework that focuses on the character of the moral agent rather than the rightness of an action” (Gardiner, 2003, p.297). In his article “A Virtue Ethics Approach to Moral Dilemmas in Medicine” he takes an in-depth look at medical ethics and he argues that there are many people who are unaware of kidney disease, the shortage of kidneys and the value of donating their organs. He suggests that a high profile campaign could have an impact on the shortage of kidneys. Velasquez and Andre’ (1996) listed five questions that people wrestle with when trying to resolve a moral dilemma. 1) What benefits and what harms will each course of action produce, and which alternative will lead to the best overall consequences? 2) What moral rights do the affected parties have, and which course of action best respects those rights? 3) Which course of action treats everyone the same, except where there is a morally justifiable reason not to, and does not show favoritism or discrimination? 4) Which course of action advances the common good? 5) Which course of action develops moral virtues? If it can be determined which individual characteristics predict NDD, educational interventions can be introduced to inclined populations that address moral questions as they relate to

kidney donation. Gardiner (2003) believes a high profile campaign could have an impact on the shortage of kidneys. Identifying which groups of people would be more inclined donate, then informing them of the need and educating them to eliminate unwarranted fears and misconceptions may increase the numbers of people who become non-directed donors.

My Interest

On December 18 2013, I became a non-directed kidney donor. Since that time, I have often been asked, “When did you decide to donate a kidney” and “Why did you become a kidney donor.” My initial response was that I have two healthy kidneys and only need one, a sentiment I since found has been shared by other non-direct donors (Tong et al., 2012). Other than that “off the cuff” answer, I realized that I had no real answer for either why or exactly when I decided to donate. The decision did not just come to me one day. It is part of a process that has been evolving throughout my life, as if it was something I was meant to do, my destiny. My experiences lead to my interest in non-directed kidney donation and the development of my 4 research questions. The questions are designed to discover more about people who are likely to become non-directed kidney donors.

Research Questions

Question #1-What are the demographic characteristics of university students who are willing to consider donating a kidney to a non-directed stranger?

Studies have been done that have begun identifying the non-directed kidney donor (Brethel-Haurwitz & Marsh, 2014; Morrissey, Dube, Gohh & Yango, 2005; Segev & Montgomery, 2008). Discovering a common profile of potential donors can be used to target these individuals. Howard (2007) and Thorne (1998) have found that promotional efforts have been successful in recruiting organ donors; therefore, creating a more refined list of likely donors has potential to improve donor recruitment.

Question #2-What are the experiences related to kidney disease, donation and transplantation of university students who are willing to consider donating a kidney to a non-directed stranger. These data can be used to determine if there are target groups of people whose lives have been affected by kidney disease and as a result may be inclined to become non-directed kidney donors. Some research on non-directed donors cites the death of a close family member while waiting for a kidney as one of the reasons people decide to become non-directed donors (Jacobs et al., 2004; Massey et al., 2010).

Question #3-What is the knowledge level about kidney disease, donation and transplantation of university students who are willing to consider donating a

kidney to a non-directed stranger? These data may be used to further determine if there are target groups of people who lack information or have misconceptions on kidney disease and transplantation and if properly educated may consider becoming non-directed kidney donors. There is a lack of knowledge about kidney donation (Dew et al., 2007), but whether or not education affects donation rates is still in question. Studies show that education about kidney donation changes attitudes and donation rates in both Hispanic and African Americans (Gordon et al., 2014; Rodrique, 2008), but Strothers, Gourlay and Liu, 2005 found that most people who donate kidneys are not necessarily better informed than people who do not donate. Since there is no consensus on whether being correctly informed about kidney disease and donation increases donation rates, further study is warranted. It is not only important to discover what motivates people to become NDD, but to identify barriers that keep them from donating (Gill et al., 2013; Reese et al., 2008; Shanker, n.d.). If it is discovered that lack of information about kidney disease or misconceptions about donation deter people from considering non-directed donation, then an education program geared towards providing factual information and dispelling myths could be developed to decrease the barrier and help narrow the gap between those who need kidneys and those who receive them.

Question #4-What is the relationship between the demographic characteristics, the knowledge and experience, and the medical altruism of university students and their willingness to consider donating a kidney to a non-directed stranger?

The more information that can be gathered, the more detailed a profile of prospective donors can be created. Hyde and White (2009b) have begun developing a prototype of the NDD. This study intends to build upon their prototype in an attempt to get a more complete understanding of people who may potentially become NDD. This was done by including a greater range of demographic characteristics than has been previously studied and attempting to find if there are any correlations between individual demographic characteristics, their personal experiences and their knowledge on kidney disease, donation, and transplantation, and their medical altruism.

There is a significant and widening gap between those who need kidneys and available kidneys. Professionals in the transplant community are increasingly embracing NDD (Morrissey & Gohh, 2015). This study attempts to identify the common qualities and characteristics of people who are open to the idea of donating a kidney to a stranger. If a profile of potential donors can be identified then both educational interventions and donation campaigns can be tailored to those individuals.

Definitions

Altruism/Altruistic- “entailing a selfless gift to others without expectation of remuneration” (Nuffield Report, 2011).

Cadaver Donor [CD] - A person who donates organs after their death. Also called a deceased donor [DD].

Chronic Kidney Disease [CKD] Chronic kidney disease occurs when the kidneys begin to lose their ability to function and waste remains in the bloodstream (Centers for Disease Control [CDC], 2014).

Diabetes - A disease in which the pancreas does not manufacture an adequate amount of insulin. As a result, the level of sugar in the blood is too high (OPTN, n.d.).

Dialysis- A medical procedure that replaces the function of the kidneys when they can no longer perform for themselves. It removes waste materials, balances body chemicals such as potassium, sodium and bicarbonate and maintains blood pressure (National Kidney Foundation (n.d.).

End-Stage Renal Disease [ESRD] - is the final stage in Chronic Kidney Disease. The kidneys fail and the patient’s treatment options are dialysis or transplantation (Medline Plus, 2014).

Graft - A transplanted organ or tissue (OPTN, n.d.).

Graft Survival - The length of time an organ functions successfully after being transplanted (OPTN, n.d.).

Human Leukocyte Antigen [HLA] –. Molecules found on cells in the body that are inherited genetically. In donor-recipient matching, HLAs help to determine compatibility between a donor and recipients (OPTN, n.d.).

Hypertension/High Blood Pressure [HBP] - Occurs when the force of the blood pushing against the walls of the blood vessels is higher than normal because the blood vessels have either become less elastic or have gotten smaller. Untreated HBP can cause kidney failure (OPTN, n.d.).

Kidney Transplant – a surgical procedure that removes a healthy functioning kidney from a healthy living or deceased donor and puts it into a person whose kidneys are no longer functioning properly (Mayo Clinic, n.d.).

Live Kidney Donor [LD]/ Live Donation [LD] – all kidney donations given while a person is alive rather than after they die. Donors may give to family, friends or strangers.

Living Related Donors [LRD] - blood family members (genetic donors) such as siblings, parents, children and cousins (NSW Health, 2014).

Living Unrelated Donors [LURD] - non-blood family or friends who have a close emotional bond with their recipients and are often spouses (NSW, 2014).

Match - The compatibility between the donor and the recipient. The more appropriate the match, the greater the chance of a successful transplant (OPTN, n.d.).

Morbidity - A disease state or the incidence or frequency of a disease among a population.

Mortality – Frequency of death among a population.

Nephrology/Nephrologists – Study/treats kidney disease.

Non-Directed Donor/Altruistic Kidney Donor/Good Samaritan Kidney Donor - people who donate to strangers without any expectations of profit or benefit and their kidney is allocated according to normal transplant center protocol which is typically the first suitable match on the waiting list (OPTN, n.d.).

Organ Procurement and Transplantation Network [OPTN] - is a unique public-private partnership that links all professionals involved in the U.S. donation and transplantation system. The goals of the OPTN are to increase the number of and access to transplants, improve survival rates after transplantation, and to promote patient safety and efficient management of the system. (OPTN, n.d.)

Paired Kidney Donors [PKD] - individuals who wish to donate to specific recipients but are not suitable matches and then are paired with another kidney patient who has a similar predicament and they “swap” kidneys to give to their respective recipients (Johns Hopkins Medicine, n.d.).

Publically Solicited Directed Donors [PSDD] - individuals who donate as a result of requests or public appeals made for kidneys for specific recipients (Steinberg, 2006; Hilhorst, 2005).

Recipient – The person with ESRD who receives a kidney from either a live or deceased kidney donor.

Renal - Referring to kidneys

United Network for Organ Sharing [UNOS] - is the private, non-profit organization that manages the nation’s organ transplant system under contract with the federal government.

Virtue Ethics - “Virtue ethics is the moral framework that puts great emphasis on the individual’s character. A virtuous person will behave rightly when presented with a situation that requires ethical deliberation” (Thomson, 2015).

2. LITERATURE REVIEW

Kidneys and Kidney Disease

The kidneys are 2 bean shaped organs, each about the size of a fist. The function of the kidneys is to filter the blood, about 120 to 150 quarts (200 liters) each day and eliminate about 1 to 2 quarts (2 liters) of waste in the form of urine (National Institute Diabetes, Digestive Disorders and Kidney Disease [NIDDK], 2014). Chronic kidney disease (CKD) occurs when the kidneys begin to lose their ability to function and waste remains in the bloodstream (Centers for Disease Control [CDC], n.d.). It develops slowly, over many years and is most commonly caused by either high blood pressure or diabetes (United States Renal Data Systems [USRDS], 2014). The percentage of each cause is represented in Figure 1. End-stage renal disease [ESRD] is the final stage in CKD (Medline Plus, 2014). Chronic kidney disease is increasing in the United States. About 10% or 3.9 million Americans are estimated to have CKD and there were 47,112 reported deaths in 2013. According to the National Health and Nutrition Examination Survey [NHANES], during the time period 1988-1994, the rate of CKD for the adult population greater than 20 years was 14.5% and for the 1999-2004 time period that percentage had increased to 16.8% (CDC, n.d.). ESRD is complete and permanent kidney failure and cannot be reversed (Am Kidney Fund, 2014; CDC, n.d.). According to National Kidney Urologic Disease Information Clearinghouse

(2014) there were 290 cases per million in 1980 and in 2009 there were 1,738 cases per million (871,000), an increase of almost 600%; however, a positive trend was noted in the 2013 USRD annual report. In 2011, ESRD incidence dropped for the first time in 30 years and remained steady in 2012.

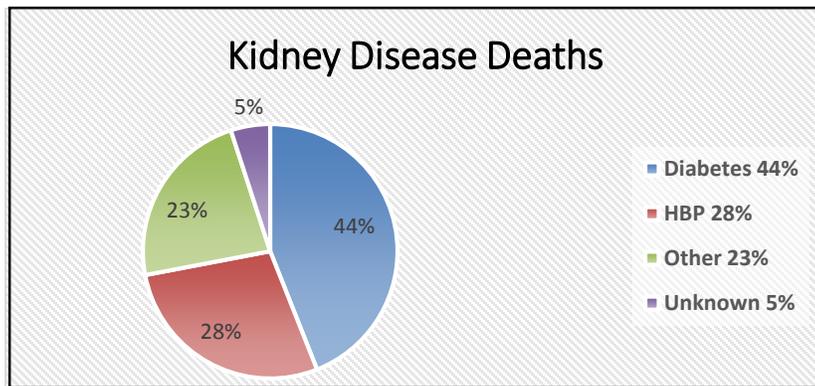


Figure 2.1 USRDS Kidney Disease Deaths 2011

Kidney Disease Treatment

When the kidneys fail, the patient has one of two treatment options, either to start on renal replacement therapy (dialysis) or to seek a transplant (Abecassis et al., 2008; American Kidney Fund, 2014). It is well established that transplantation is the treatment of choice for ESRD patients (Tonelli et al., 2011). Dialysis is more costly and is less effective, more restrictive, and lowers the quality of life (Berns, Brennan & Sheridan, 2013; Beth Israel Deaconess Medical Center, n.d.; Port, Wolfe, Mauger, Berling & Jiang, 1993). According to the National Kidney Foundation [NKF] (n.d.), life expectancy on dialysis is typically

5-10 years, but many patients have lived more than 30 years. Savings incurred over costly dialysis (Caliskan & Yildiz, 2012; Mueller, Case & Hook, 2008) are estimated to be \$100,000 per patient (Whiting et al., 2004).

Kidneys for transplant come from both living donors (LD) and cadaver donations (CD). Kidneys that come from living donors have better outcomes than do those that come from cadaver donors (Koo et al., 1999; Port et al., 1993; Terasaki, Cecka, Gjertson & Takemoto, 1995). According to the 2012 United States Renal Data System [USRDS] annual report, graft failure of living donor kidneys is 3.2%, 15.4% and 38% for 1, 5 and 10 years respectively as compared to 8.5%, 29% and 54% for cadaver kidneys. The Organ Procurement Transplantation Network [OPTN] (2012) shows similar rates. Their data are reported in graft survival rates. Graft-censored survival rates for living kidneys are 94.4%, 92.6% and 88.1% at 1, 3 and 5 years respectively. Five year graft survival for deceased donor transplants is 73% and for living donor transplants is 84%. In Figure 2, the NKF (2015) illustrates the increased longevity for transplant recipients of living compared to cadaver kidneys.

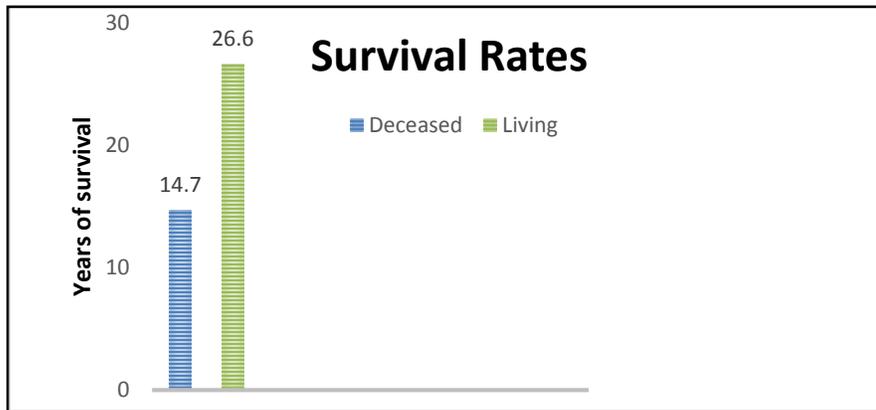


Figure 2.2 Survival Years-Deceased & Living Donors National Kidney Registry (2015)

Traditionally, kidneys have come from family members, but the donor outcomes of living unrelated donors [LURD] are similar to that of all living donors [LD] and there is no difference between the graft failure rates of non-directed donors [NDD] and other unrelated donors (Gjertson & Cecka, 2000; Segev & Montgomery, 2008).

An additional benefit of living donation over cadaver donation is that the transplant surgery can be scheduled at a time convenient to both the donor and the recipient (Gill, et al., 2005; Living Donors Online, n.d.) and at a time when the donor and recipient are optimally healthy (Gjertson, & Cecka, 2000; Mueller et al., 2008). With living donation, some transplants can be performed pre-emptively, without the patient ever having to go on costly dialysis.

Unfortunately, only 2.5% of patients get a transplant before they spend at least some time on dialysis (Abecassis et al., 2008). This strategy is preferable because

the longer a person is on dialysis, the less favorable the transplant outcome (Sotiropoulos & Brokolaki, 2004). Besides the considerable cost savings, patients who undergo pre-emptive transplantation have better outcomes than those who are on dialysis prior to transplant (Friedewald & Reese, 2012; Terasaki, et al. 1995).

Kidney Shortage

There is an increasing gap between the number of people needing kidneys and the number of kidneys available (Ge, Kaczmarczyk, & Biller-Andorno, 2014; Oliver, Ahmed, & Woywodt, 2012). In 2012, there were about 17,300 transplants and just shy of 35,000 names were added to the waitlist (Cook & Krawiec, 2014). The wait time for a kidney transplant is between 2.5 and 5 years, depending on the blood type (Kranenburg, et al. 2008; OPTN, 2012; USRD, 2013) and can exceed 10 years (Gill et al., 2005; Ojo et al., 2001). According to the LivingBank (2015) an organ transplant advocacy organization, as of February 13 2015, there were 109,446 people on the national organ transplant wait-list awaiting a kidney. The wait times have increased from 2.7 years in 1998 to 4.2 years in 2008 (OPTN, 2012). Another alarming statistic is the assessed probability of dying each subsequent year on the waitlist. The risk of dying increases as follows; after the 1st year it is 1.3%, the 2nd year 4.0%, the 3rd year 8.7%, the 4th year 13.8%, and after 5 years 19.8%. In the United States in 2013, 4453 people died while waiting for a

kidney transplant (NKF, n.d.), about 6.3% of all patients on the waiting the list.

According to UNOS (n.d.), approximately 22 people die daily awaiting a kidney.

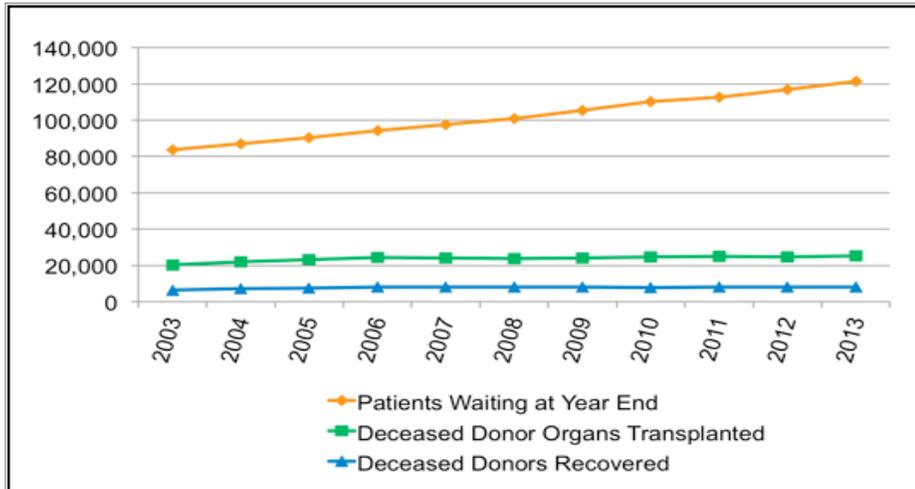


Figure 2.3 OPTN 2014 Waitlist for Organ Transplant

There is a disparity between which populations are most in need of kidneys and which populations receive them (UNOS, n.d.). Blacks and Hispanics are in the greatest need, but receive fewer available kidneys than do Caucasians (Gordon et al. 2014; Reese, Boudville & Garg, 2015; Waterman, Rodrique, Purnell & Ladin, 2010). Each year, approximately 6000 people in the United States receive live organ transplants, most of them from kidneys (UNOS, n.d.). According to UNOS statistics through June 8 2015, there have been 372,563 kidney transplants in the U.S. The ethnicity breakdown is as follows: White (57%), Black (24%), and Hispanic (13%). This inequity has been noted as recently

as 2014. There were 17,106 kidney transplants performed. Whites received 8,613 (50%), Blacks 4317 (25%), and Hispanics 2738 (16%). When you compare transplants done compared to the numbers on the wait-list for kidneys, the imbalance becomes apparent. Using the 2014 UNOS data, there are 109,533 on the U.S. waitlist; 40,122 (37%) are white, 37,243 (34%) are Black, and 21,073 (19%) are Hispanic. Gordon et al. (2014) report that in the United States in 2011, Hispanics received fewer live kidneys (15.2%) than their need illustrated by the 19% on the waiting list. The disproportionate distribution of kidneys is also true for non-directed donations [NDD], those donations that are anonymous and going to unnamed recipients. Segev and Montgomery (2008) studied the 372 non-directed donors from transplants performed in the U.S. from 1998 to that time. Their data reflect a similar disparity in the populations needing and those receiving the kidneys.

This disparity is in part because Blacks and Hispanics are less likely to donate (OPTN, 2012), even to family and friends. It is not entirely known the reason for the reluctance, but a number of ideas have been suggested, 1) minority populations have a well-documented distrust of the medical community (American Transplant Foundation, n.d.; Waterman et al., 2010), 2) they are less likely to be aware of the benefits of live organ transplantation (Irving et al., 2011), 3) they are less likely to meet the stringent health requirements necessary to

donate because they have diabetes, HBP or other disqualifying medical conditions (Davis & Delmonico, 2005; Reese et al., 2015), 4) they mistakenly believe their religion prohibits donation (Kidney Buzz, n.d.), 5) they fear donation due to misconceptions they hold about kidney disease and donation (Shankar, n.d.), 6) they cannot afford to miss work or they have jobs that do not allow for time off (Reese et al., 2015), 7) they are uninsured and they incorrectly believe that they would be financially responsible for their medical expenses, and 7) they are unable to manage any financial burden their donation may cause (Gordon et al., 2014; Reese et al., 2015).

With the shortage of organs, living donors have become a viable source of kidneys. It is no longer necessary to be a Human Leukocyte Antigen [HLA] match to be a suitable kidney donor (Terasaki et al., 1995; Voiculescu et al., 2003). This opens the door for non-blood-related family, spouses, friends, acquaintances, and even strangers to become donors (Gohh & Morrissey, 2001; Steinberg, 2006; Truog, 2005).

Living Donors

There are 5 classifications of living donors: 1) Living Related Donors [LRD] are blood family members (genetic donors) such as siblings, parents, children and cousins (Living Donors Online, n.d.) 2) Living Unrelated Donors [LURD] are non-blood family or friends who have close emotional bonds with

their recipients and are often spouses (Living Donors Online, n.d.), 3) Publically Solicited Directed Donors [PSDD] are individuals who donate as a result of requests or public appeals made for kidneys for specific recipients. These requests come from news sources, religious congregations, worksites, social groups, Craigslist, social media sites such as Facebook, billboards, and websites designed specifically to match needy recipients with willing donors e.g., Matchingdonors.com (Steinberg, 2006; Hilhorst, 2005), 4) Non-Directed Donors [NDD], sometimes called Altruistic or Good Samaritan donors are people who donate to strangers without any expectations of profit or benefit and their kidneys are allocated according to normal transplant center protocol which is typically the first suitable match on the waiting list (Delmonico, 2004; Munson, 2002) and 5) Paired Kidney Donors [PKD] are individuals who wish to donate to specific recipients, but are not suitable matches and then are paired with another kidney patient who has a similar predicament and they “swap” kidneys to give to their respective recipients (Johns Hopkins Medicine, n.d.; Woodle et al., 2010). Figure 4 illustrates a paired kidney exchange (Johns Hopkins Medical Center, n.d.)

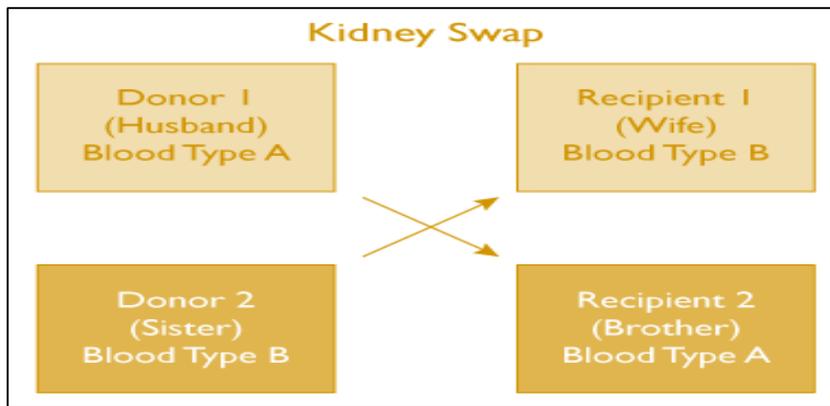


Figure 2.4 Paired Kidney Donation
Johns Hopkins Medical Center

Living Donation

In 2001, for the first time in U.S. history, donations from living donors [LD] were greater than those from deceased (cadaver) donors (UNOS, n.d.). The decade prior to 2004 experienced a 120% overall increase in LD and when looking back to 1988, the increase is 265% with each year seeing a greater increase than the previous (Rodrigue, Schold & Mandelbrot, 2013). This pattern only lasted for a few years and since that time, LD have been on the decline (Gill et al., 2013; Glotzer, Singh, Gallichio, Conti & Siparsky, 2013). According to the United States Department of Health and Human Services Organ Procurement Transplant Network [OPTN], the number of live donor transplants peaked at 6647 in 2004, and fell by 10% to 5989 in 2005 (Reese et al., 2015). Since 2004, there is only one year (2009) that donation numbers increased and from the years 2004 to 2013, the less successful deceased (cadaver) donations were greater than live

donations (OPTN, n.d.; United States Organ Transplantation, 2010). By 2013, of the 16,896 kidney transplants in the United States, 5,733 came from living donors and 11,163 came from deceased donors (National Kidney Foundation, n.d.).

Although living donations have decreased overall, according to the OPTN 2014 annual report, living unrelated donations have increased [LURD]. They jumped from 7.1% of total living donor [LD] donations, 287 of the 4059 transplants in 1997 to 23.6% of LD, 1589 of 6732 transplants in 2006. Most of the donations are directed donations [DD], donations that come from non-blood related family members or friends (Epstein & Danovitch, 2009) and not non-directed donations which only account for about 3% of all living donations (USDHHS, 2013).

Living kidney donor/recipient relationships have changed. Until the recent past, living donors were primarily blood-related family members (OPTN, n.d.). In 1999, 68% of donations were from living related donors: full siblings (35%), parents (17%), and offspring (16%). With technological advances in anti-rejections drugs, today kidney transplants have a high rate of success even when the donor and the recipient are not close genetic matches (Cecka, 2003; Davis & Delmonico, 2005). Graft survival rates are excellent for kidneys received from non-related donors (Gjertson & Cecka, 2000; Terasaki et al., 1995). Outcomes are similar when comparing kidneys from living related donors to those from living

unrelated donors [LURD] (Davis & Delmonico, 2005; Manauis et al., 2008). There are a considerable number of people who do not have living blood relatives who are willing and able to donate their kidneys. Medical professionals now look to LURD to meet this need. Increasing the donor pool to include this type of donor exponentially increases the number of potential donors. The good news is that while overall living donations are down, living unrelated donations are increasing (Dew et al., 2007; Massey et al., 2010) and is the only source of donations that has seen increases over the last 15 years. In 1997, LURD were 6.1% of donations and they jumped to 23.6% in 2006 (OPTN, n.d.). During the years 2007 and 2008, 35% of living kidney donors were not biologically related (Dew, Switzer, DiMartini, Myaskovsky, Crowley-Matoka, 2007; Mueller et al., 2008). Figure 5 illustrates the 2012 donor/recipient relationship. Donations from family are declining. Donations from full siblings decreased to 20%, donations from children to parents decreased to 14 %, and parents to children fell to only 8% of all donations. On the other hand, donations from spouses and close friends accounted for 35%. Also encouraging is that donations from non-directed kidney donors [NDD] are increasing (Boulware et al., 2005; Massey et al., 2010) and more than half of all 1,374 NDD recorded in the U.S. through the year 2012 had occurred since April 2009 (Karlmanangla, 2013).

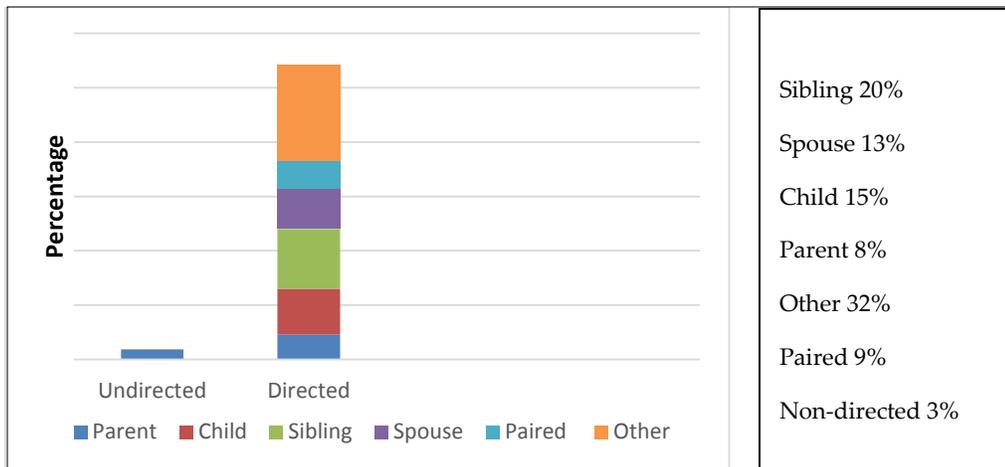


Figure 2.5 Kidney Donors by Relation-2012
U.S. Department of Health and Human Services

A type of living donation is non-directed donation. In much of the literature, non-directed donation [NDD] is called either altruistic or Good Samaritan donation. I will choose to use NDD. Using the term altruistic donation for this category of donor somehow suggests that other types of organ donors are not altruistic (livingdonor.com). The term also implies a sort of selflessness or virtue which makes me, as a donor uncomfortable and unworthy of such a label. It also implies that there is no benefit to the donor which much of the research disputes (Corley, Elswick, Sargeant & Scott, 2000; Fellner, 1977; Johnson et al., 1999).

While living donation is on the decline, the numbers waiting for kidneys continues to climb. By 2013, the number of kidney patients needing transplants was three times greater than the number of available donor kidneys (USRDS,

2013). There is a sense of urgency to find ways to increase living donation, particularly non-directed donation.

Ethics and Living Donation

Living donation [LD] is in its infancy and has met with skepticism among both medical professionals and the general public. Ethical concerns have divided the medical community (Clemens et al., 2006). Physicians must justify putting a healthy person's wellbeing at risk to improve the life of an already sick patient (Truog, 2005). It is also difficult for many to fathom why someone would donate a kidney and assume its health risks while gaining no obvious personal benefit (Cecka, 2000; Mjøen et al., 2011). Donors' mental stability and motivations are suspect. The transplant community must balance the needs and interests of both the kidney patient and the donor. The New South Wales [NSW] Australia Guidelines for Living Kidney Donation lists the need to make the interests of the donor and the recipient of equal importance (NSW, 2015). As early as 2000, a group of more than 100 individuals from the world transplant community with representatives from the National Kidney Foundation, the American Societies of Transplantation, Transplant Surgeons, and Nephrology met to deliberate on the ethical and controversial issues that surround live kidney donation. They released a consensus document that included a statement declaring that the

benefits to the donor and recipient must outweigh the risks (Abecassis et al., 2000).

Another ethical dilemma central to living donation concerns informed consent (Caliskan & Yildiz, 2012), questioning whether the donation is truly voluntary. In addition to these concerns are those specific to the various types of living donation (Moorlock, Ives & Draper, 2014; Truog, 2005).

Living Directed Donor

Living directed donation [LDD] occurs when someone donates with a specific recipient in mind and according to UNOS data (2014) it comprises about 99% of all kidney donations since 1988. Of those LDD, about 75% come from living blood relatives [LRD]. Coercion is a common concern that arises with LRD. It is unsettling to many that apprehensive donors may be unable to resist the insurmountable pressure exerted from family and friends (Truog, 2005) or that some donors may make unreasonable demands on their recipients in trade for their kidneys (Matas, Garvey, Jacobs & Kahn, 2000). Additionally, there is concern about donor motivations. Donating out of guilt or donating to atone for past transgressions are “red flags” to transplant professionals (Massey et al. 2010).

Most of the remaining living directed donors come from unrelated donors, either non-related family such as spouses or from close friends (UNOS, n.d.). The

ability to give informed consent, possible coercion to donate, and the mental health of the donor are again concerns. Attention seeking and approval, increasing self-esteem, self-importance and societal approval through media attention are also questionable motives (Beauchamp and Childress, 2001; Roff, 2007). However, possibly the most expressed fear is the slippery slope (Bia et al., 1995). Fears of commercialization, public solicitation, exploitation, and the sale of kidneys are troublesome possibilities (Dew et al., 2007; Rodrigue et al., 2007; Soho, 1999).

Ethics and Non-Directed Donation

The type of donation that has garnered the greatest trepidation is the non-directed donation [NDD] (Boulware et al., 2005; Gilbert, Brigham, Batty & Veatch, 2005; Gohh & Morrissey, 2001). These donors are strangers who volunteer their kidneys with no expectation of personal gain and seemingly receive no benefit from donating (Baskin, 2009; Kranenburg et al., 2008). When you analyze the risk/reward balance experienced by the donor, the ethical challenges facing the medical community are daunting (Reese et al., 2015; Ross, 2002; Spital, 2004). On the surface, NDD appears to violate the Hippocratic “Do No Harm” edict which throughout the history of medicine has been an ethical compass by which physicians practice. The questions that need to be addressed are “do the benefits to the donor outweigh the inherent risks of the surgery” and

“are physicians really ‘doing no harm’ when subjecting a healthy person to the physical and psychological risks of transplant surgery in order to help an already seriously ill patient (Cecka, 2000 & Challenor & Watts, 2014).

Some physicians believe that the health risks are substantial and outweigh the benefits to the donor which they believe are little to none (Challenor & Watts, 2014; & Landolt et al., 2001). Living kidney donation [LKD] affords virtually no physical benefits to the donor. The only real benefit is the possible increased consideration for placement on the recipient list in the unlikely scenario their single kidney goes into failure (Baskin, 2009). The concerns are different for living directed donors [LDD] than they are for living non-directed donors [NDD]. There are obvious benefits for LDD. They have the opportunity to see the health improvement of a loved one. Whether there are psychological benefits to NDD is questionable (Henderson et al., 2003; Massey et al., 2010). Because of the seeming imbalance of risk to reward, donor motivations have been suspect and there is a history of believing that people who volunteer to be NDD are psychologically imbalanced (Clarke, Mitchell & Abraham, 2014; Dew et al., 2007; Rodrigue, 2007). Ross (2002) challenges the claim that there are no benefits. She argues that there are both psychological and moral benefits to NDD; therefore claims the principle of nonmaleficence does not apply. Others have also found that NDD benefit from the gift of donation, itself. Lennerling, Forsberg, Meyer &

Nyberg (2004) and Landolt et al., (2001) contend that it is possible that non-directed donors have greater ethical, psychological and sociological outcomes than living directed donors [LDD] and their donation is more ethically sound because it is without external coercion. Considering that they are not motivated by emotional ties or obligation to the recipient; they have nothing personal at stake: their motivations are pure and their consent is unquestionable (Lennerling et al. 2004).

Transplant professionals report additional concerns. Some disconcerting motivations they note include 1) profiting from donation (Massey et al., 2010; Truog, 2005), 2) placing conditions in an attempt to manipulate who does or does not get the donated kidney (Matas et al., 2000; Moorlock et al., 2014), 3) wishing to become personally involved in the recipient's life (Truog, 2014), and 4) seeking approval through accolades and media attention (Jacobs, Roman, Garvey, Kahn & Matas, 2004; Massey et al., 2010).

Non-directed donation warrants further research. Who are the people who offer to donate their kidneys to strangers? Are they psychologically healthy and competent to consent? Are the physical and psychological outcomes to the donor worth the risk? And if the answers to any of the above questions are yes, then we have an obligation to look further into who these donors are. Are there certain characteristics and life experiences that increase the likelihood of people to

donate and does Knowledge on Kidney Disease, Donation, and Transplantation increase or decrease willingness to consider NDD. Isolating a donor profile can be used to target potential NDD with the hope of increasing NDD and making a dent in the gap between those who need kidneys and available kidneys.

Characteristics of Live Kidney Donors

When investigating the profile of living kidney donors in the United States, it has been found that women donate more often than men (Kayler et al., 2003; OPTN, n.d.; Zimmerman, Donnelly, Miller, Stewart & Albert, 2000). Of the 128,507 people who donated between 1988 and 2015, nearly 60% were female and female donations exceeded males in every one of those years. Studies done on living donors at varying transplant centers found different ratios of men to women. Jendrisak et al. (2006) conducted a study of individuals who inquired about NDD at one of two transplant centers in the St. Louis area. Their data show 65% of those who inquired were female as were all 6 who actually donated. Morrissey et al., (2005) had similar findings at their transplant center in Rhode Island. They studied 18 individuals who donated to strangers, 11 were NDD and 7 donated to specific predetermined strangers (directed stranger donation). Fifteen (83%) of the donors were female. Research in 2006 by Mark, Baker, Aguayo & Sorensen (Intermountain Donation Services) and in 2005 by Gilbert et al. (Washington D.C. area) had different outcomes than the previous studies;

each counted the same numbers of men as women, 10 and 5 respectively. Jacobs et al. (2004) found that 68% of the 22 donors in their Minnesota clinic were male. Segev and Montgomery (2008) inspected all the 372 non-directed kidney donations that occurred in the United States between the years 1998 and 2005, these numbers include most of the NDD counted in the previously cited studies, and found that 55.9% of the donors were female and the remaining 44.1% were male. A more recent review of the male/female breakdown of NDD was conducted by The Organ Procurement Transplant Network [OPTN]. OPTN has kept records of all U.S. organ donations since 1999. Between the years 1999 and 2010 there were 955 NDD in the United States and 56% were female. The percentage of men and women was virtually the same in the OPTN numbers and the earlier Segev and Montgomery (2008) report. On the surface it looks as though there has been no change, but the OPTN data includes the Segev and Montgomery numbers so in reality, there is a small increase in male donors.

The mean age of living donors falls in the early to mid-40's (Clemens et al., 2006; Gross et al., 2013; Strothers, Gourlay & Liu, 2005). OPTN does not collect organ specific donor information by age so its numbers reflect all live organ donations, not just kidney. In the time period cited, kidneys represented 95.5% of all donated organs so the information is useful and reflects true patterns. Of the 134,422 organs donated, 99% of the donors were between the ages of 18 and 64.

Seventy eight percent were between the ages of 18 and 49 (OPTN, n.d.). The average age of non-directed donors [NDD] is somewhat higher than that of all living donors. Segev & Montgomery (2008) found that of all U.S. NDD through 2005, 93% were between the ages of 18 and 59, with 63% in 40-59 age range. OPTN (2010) data show that 58% were between the ages of 35 and 54. Tong et al., (2012) studied all NDD in New Zealand from 1998-2010. Of the 18 NDD, 72% (13) were between the ages of 41 and 60. Maple, Chilcot, Burnapp & Gibbs (2014) found the average age of NDD in the United Kingdom to be 54 while the directed donor was 44. A possible explanation of why NDD are slightly older than all living donors is that non-direct donation may be a gift of opportunity, where directed donation [DD] is a gift of necessity. People who donate to family and friends do not have the convenience of donating when the circumstances are ideal, when they have the time, when they are financially stable; they donate when their loved ones are in need. NDD make a personal choice to donate when the time is right, when their “ducks are in a line”. The kidney donation preparation process is long, tedious and the surgery is life interrupting. Donors have to disrupt their normal routines, spend a few days in the hospital and it can take as long as a few months until they are back to pre-surgery life. For many this involves lost work, income and a suspension of regular activities. Because DD are most often donating to loved ones, the disruption may be worth it, but

the NDD has a choice to wait until life circumstances are ideal. Older adults are more likely to have stable incomes, kids who are no longer in their households and more control over their environments.

Caucasians donate the largest percentage of live kidneys including both through directed and non-directed donations. In individual studies, percentages range from 89% to 95% of all donors (Clemens et al., 2011; Gross et al., 2013; Maple et al., 2014; Strothers et al., 2005). OPTN data report that from January 1 1988 to April 3 2015 there were 128,507 live kidney transplants in the United States. White donors accounted for 90,535 (70.5%) of all donors. Other race/ethnicities donation rates were as follows: Black 16,017 (12.5%); Hispanic 16,052 (12.5%); Asian 3,642 (.028%); American Indian/Alaska Native, Pacific Islander & Multi-Racial 2,062 combined (.016%); and 109 donors' ethnicity is unknown.

Non-directed donors [NDD] in the United States are also overwhelmingly Caucasian and this pattern is similar throughout the world. With the exception of Jendrisak et al., (2006) who reported four Caucasian and two African Americans, all other studies reported between 94% and 100% of NDD were Caucasian. Mark et al., (2006) report that 100% of their NDD were Caucasian. Segev & Montgomery (2008) report the following rates; 94.4% Caucasian, 2.2% Asian, 1.6% African American, 1.1% Hispanic, and .08 other. All 18 (100%) of NND in

New Zealand between 1998 and 2010 were Caucasian (Tong et al. 2008). OPTN data show the Race/Ethnicity breakdown of NDD to be White Non-Hispanic 92%, Hispanic 2.5%, Black 3%, Asian 1.5%, American Indian/Alaska Native, and multiracial combined less than .1%. The data show a small increase in non-Caucasian NDD. Even though there was only a 2% decrease in Caucasian donors noted when comparing the Segev & Montgomery (2008) data with the OPTN (2010) data, it must be noted that the OPTN data includes the 372 NDD reported by Segev & Montgomery so the increase is more impressive than it appears on the surface.

Several research studies investigated whether income and education levels have an impact on donation rates. Strothers et al. (2005) examined the differences between people who donated their kidneys to needy family members and those who chose not to donate. Using data from their transplant center in Vancouver, British Columbia, they found that 63% of the people who donated earned between \$30,000 and \$100,000 annually and those with higher incomes were more likely to donate than people with lower incomes. Gill et al. (2013) had similar results. They studied the effect of income and race on donation rates and found a powerful association between median household income, determined by zip code, and rates of living organ donation.

Education level may also be a factor in donation. Living donors seem to be more educated than non-donors with many having college and advanced degrees (Gross et al., 2013; Siegel, Alvaro, Lac & Crano, 2008; Strothers, 2005). Tong et al. (2012) studied 18 of the 19 non-directed donors [NDD] in New Zealand from 1998 to 2010 and found that 13 of the 18 donors (72%) had college educations. Studies of NDD patterns in regions of the U.S. show similar findings; the greater the education the more likely one is to donate (Jacobs et al., 2005; Mark et al., 2006; Morrissey et al., 2005). Segev and Montgomery (2008) reviewed data from all U.S. NDD (372) between January 1998 and June 2006 and report that 82.6% of all donors were college educated.

Brethel-Haurwitz and Marsh (2014) noted that in the United States there was a significant difference in the geographical clustering of non-direct donors [NDD]. Researchers wondered if subjective well-being was related to the act of non-directed donation. They compared data on geographical well-being by state (Gallop, 2012) to state per capita NDD. Well-being was measured by self-reported data on life satisfaction; physical and emotional health; work environment; meeting of basic needs; and practicing healthy behavior. They found that well-being predicted donation.

Although most major religions in the world support organ donation, some even encourage it and no major religion strictly forbids it (Bruzzone, 2008), there

is some variation among religions and individuals' knowledge and interpretation of their religious doctrine regarding donation (Oliver et al., 2012). It is not uncommon for people to make decisions about kidney donation based on their religious beliefs (Mueller et al., 2008). Many non-donors claim their religious beliefs are in part the reason they choose not to donate (Oliver et al., 2010; Wakefield, Reid & Homewood, 2012). Blacks of African descent often cite religion, either Christian or Muslim, as a reason for their decision not to donate (Davis & Ranshawa, 2006). Misconceptions or ignorance about their religion's stance on donation affects donation rates. For that reason, Catholic donation lags behind many other major religions even though the Vatican has made a public statement supporting organ donation (Kidney Buzz, 2015). However, religious beliefs can also be responsible for people choosing to become NDD (Dixon & Abbey, 2000; Jacobs et al., 2004 & UNOS, n.d.). Henderson et al. (2003) found that people who were responded positively to NDD were more likely to claim a spiritual belief system than those who were not.

Public Opinion on Non-Directed Donation

Some early research has been done on public acceptance of the practice of living unrelated kidney donation [LUKD]. Spital & Spital (1988) found of those surveyed, 77% said donating a kidney to a friend was acceptable and 70% believed it was acceptable to donate to a stranger. The first studies conducted

asking people about their willingness to be non-directed donors were conducted in the early 1970s. Sadler et al. (1971) found that 52% might consider donating to a stranger; 19% of those surveyed said they would donate, and 33% said they were uncertain. The second 1971 study had similar findings. Fellner & Schwartz found that 54% would likely donate to a stranger; 11% responded definitely and 43% said probably. The following year, Gade (1972) found that 41% would consider donating to a stranger. In 1985, Stiller, et al. reported that 26% of those surveyed would consider NDD.

Later studies show similar patterns of willingness. In 2001, three different studies investigated attitudes towards non-directed kidney donation. Spital (2001) looked at both public perception of living unrelated kidney donation [LURD] and personal willingness to donate. His data show that a large majority approved of both donating to a friend and donating to a stranger, 90% and 80% respectively. Asking about their personal behavior, 24% percent claimed they would definitely donate to a stranger and an additional 21% said they probably would. This was true even after being informed about the risks of major surgery. Also in 2001, Intermountain Donor Services, an organ procurement organization [OPO] that services close to three million people primarily in Utah conducted a local survey. They found that 49% of the respondents would be willing to donate a kidney to someone they did not know and 19% of them claimed if it was

necessary, they would do so within the year (Mark et al. 2006). The survey was repeated in 2003 with similar findings. The third 2001 study was done in British Columbia, Canada. Twenty nine percent of British Columbia residents surveyed said they would consider donating to a stranger (Henderson et al.). Two things of note, all of the previous studies had relatively small sample sizes and they were done before the less invasive laparoscopic option for surgery was common practice.

Two more recent and much larger studies asked about people's inclination towards non-directed donation. In 2012, the U.S. Department of Health and Human Services, Health Resources and Services Administration division polled more than 3,000 adults inquiring about their willingness to be live kidney donors. Not surprisingly, the closer the relationship to the person in need, the more willing people were to donate. Willingness ranged from 93.5% to a family member to 54.7 % to a stranger. In 2013, the Mayo Clinic conducted slightly more than 1000 telephone interviews and found that 49% said they would be either very likely or somewhat likely to donate a kidney to a stranger.

Profile of the Non-Directed Donor

Recent research on identifying potential non-directed donors [NDD] is reasonably sparse and of the seven studies referenced here, four different countries are represented. The 8th study, done by Wakefield, Watts, Homewood,

Meier and Smirnoff (2010) perused all the international literature that examined attitudes toward organ donation. While there is no indication that the country studied affected the findings, the variety of countries should be noted.

The studies: 1) Landolt, Henderson, Barrable & Greenwood (2001) conducted a study in British Columbia, Canada asking residents about their willingness to donate their kidney to a stranger, 2) Boulware et al. (2005), Johns Hopkins Medical Center surveyed and compared the attitudes of people who inquired about NDD to those of the general public, 3) the Mayo Clinic (2013) conducted a telephone survey asking more than 1000 Americans about their willingness to donate their kidney to a stranger, 4) The U.S. Department of Health and Human Services HRSA [DHHS] (2013) National Survey of Organ Donation Attitudes and Behaviors asked 3000+ Americans about their willingness to donate to a stranger, 5) Hyde & White (2009a) studied Australians' willingness to donate to a stranger, 6) Challenor & Watts (2014) conducted a case study of 6 individuals who inquired and were found suitable for NDD in the United Kingdom and 7) Wakefield et al. (2010) reviewed all international literature that studied organ donor attitudes and behaviors.

Profile of Willing Donors

This paper will use the preceding studies to paint a picture of those individuals who are potential non-directed donors. Each study refers to these

people somewhat differently, but for the sake of clarity, the terms willing donors/willing donation [WD] and non-willing donors/non-willing donation [NWD] will be used. For ease of reading and flow, the following section will use the last name of the first author only.

Most of the studies found WD were more likely female than male (Boulware, 2005; DHHS, 2013; Wakefield, 2010). Landolt (2001) however, found no significant differences. The DHHS found that in every age group with the exception of the 60+, greater than 50% of the respondents said they were either very likely or somewhat likely to donate a kidney to a stranger. The most likely age to be WD is middle age (Boulware, 2005). This may be because they are less likely to have children at home, but not old enough to worry about the viability of their organs or their own health issues (Landolt, 2001). WD, just as with people who have already donated are predominately Caucasian. According to Boulware (2005), of the 40 people studied, 85% (34) were White, 8% (3) Hispanic; 3% (1) Black; 3 & 2 (5%) Other. WD are more likely to be married or living with others rather than single (Landolt, 2001; Boulware, 2005) and have higher incomes (Landolt, 2001; Wakefield, 2010).

A few of these studies also evaluated the attitudes and behaviors of WD. In the Boulware (2005) study, WD were no more altruistic than NWD, but Wakefield (2011) found a different outcome when perusing the bulk of literature.

Most studies show that altruism was greater in WD than NWD. Medical Altruism is a specific form of altruistic behavior and is frequently noted in WD. They are more likely to be deceased organ donors (Hyde & White, 2009; Landolt, 2001; Wakefield, 2010), have donated blood (Boulware, 2005; Hyde & White, 2009), or are on the national bone marrow donor registry (Jendrisak, 2006). Whether or not religion or religiosity has an impact on donor willingness varies depending on the study. Although Boulware (2005) found no difference in religiosity in WD compared NWD, Hyde and White (2009) found that having a religious affiliation made willing donation more likely and Wakefield (2011) found that willing donors were less likely to claim a religious foundation.

A common theme found in WD is what is called a donor personality (Landolt; Piliavin, 1990); their image of themselves is consistent with donating (Challenor & Watts, 2014; Hyde & White, 2009). They see donating as part of who they are and what is expected of them. WD also express a genuine interest in helping others and believe that their donation will help people live better lives (Challenor & Watts, 2014; Landolt, 2001). Willing donors tend to minimize the risk of the donation process and deem it insignificant compared to its benefits. In fact, participants in the Boulware (2005) study were willing to accept greater risks than were actual risks and researchers found that having the correct information had no effect one way or the other on their desire to donate

(Boulware, 2005). Decisions seem to be more based on personal and emotional factors than factual information.

Another factor that may influence donation rates is one's experience with the medical system. WD professed to have confidence in the medical profession (Challenor & Watts, 2013; Clarke, 2014; Landolt, 2005; Massey et al. 2010; Tong et al., 2012). It is commonly accepted that Blacks and Hispanics harbor a deep seated mistrust of the medical profession (Gordon et al., 2014; Siegel et al., 2008) and are suspect of physicians' intentions and motivations. This suspicion is not without merit. Health care in America affords fewer options and shows poorer outcomes for minority Americans than for their non-minority counterparts (Mead et al., 2008). As new and rare as non-directed donation is, a disparity in the allocation of donated organs has already emerged. Segev and Montgomery (2008) report that African Americans represent 33.1% of patients on the kidney transplant waitlist and received only 19.5% of the organs compared to Caucasians who represented 42.3% on the waitlist and were allocated 64.7% of the non-directed donations. In addition, the donation process is long and arduous and Waterman et al. (2010) suggest that the medical process itself is a roadblock for potential living donors, especially for people who have less education or experience with the medical profession. With the issues of

familiarity and trust, it is apparent that experience with the medical profession influences WD.

Outcomes of Living Donation

Much of the resistance to non-directed donation is fear about the physical and psychological impact of the donation process on the donor. In the United Kingdom, Lumsdaine et al. (2005) studied living donors (40) and recipients (30). They found that after one year, donors report no negative outcomes either physically or psychologically and that recipients experienced greatly improved well-being. Anderson et al. (2007) conducted follow-up interviews with 12 living kidney donors and noted that a few experienced some unanticipated problems. Donors reported some depression and sense of loss; experienced a longer recovery than expected; and they report considerable distress if their recipients' outcomes were not good. Boudville, Prasad & Knoll (2006) conducted a meta-analysis and noted a 5mm Hg increase in blood pressure in a 5-10- year period following donation. The authors present a number of limitations, but since the increase is small they report no clinical implications for their findings.

Even with the potential physical concerns, the literature is clear that the long term risks are minimal and the potential gain is considerable. Donor long-term survival rates are similar to the general population and the quality of life outcomes are as good or better (Ibrahim et al. 2009). When reviewing the

literature on living donors, the conclusions can be recapitulated by two meta-analyses. Ummel, Achille and Mekkelholt (2011) conducted a review of 15 qualitative studies with a methodology of either focus groups or subject interviews. Data show that there were some physical challenges that donors faced and some expressed they had not been adequately prepared for them; however, this did not seem to impact the overwhelming feeling of satisfaction that most donors report. Most expressed no regrets and many claimed they personally benefited from the process.

Clemens et al. (2006) evaluated 51 studies from 19 countries between 1969 and 2006. They found that although studies report that following donation some donors expressed a few less than positive outcomes: increased stress related to the process, concern about their own health, unmet expectations, feelings of not being appreciated and sadness or regret if their recipients had poor outcomes, the overwhelming response to the process was positive. Many donors expressed an increase in self-esteem and self-satisfaction. Some benefits commonly reported were feeling proud, courageous, accomplished, and gaining a deeper religious faith. Studies overwhelmingly convey following donation that the majority of patients showed no mental health problems. A large percentage report being happy, and in one study more than 80% were happier after donation. Various studies showed the following; donors were calmer, more content, happier and

more cheerful, and expressed an increased opinion about themselves and others. In the 29 studies reviewed by Clemens et al. that examined the quality of life, living donors reported having a high quality of life following donation, both similar to and often greater than the general population.

The psychological well-being of non-directed donors has historically been worrisome. As early as 1971, Sadler et al. interviewed nine NDD and found no evidence of psychological pathology or regret in their decisions to donate. Forty years later, Rodrigue, Schultz, Paek & Morrissey (2011) found that NDD had comparably good psychological outcomes as other living donors. To further address this concern, Kranenburg et al. (2007) conducted a systematic review of the literature investigating the psychological profile of the NDD. They found that there was no standardization of the donor evaluation process or of the types of behaviors and motives that excluded people from donating. They did note that the standards that were being applied appeared to be much more rigid than those for living directed donors [LDD]. The Rodrigue et al. (2007) data show that 75% of 132 surveyed U.S. kidney transplant centers require psychosocial evaluation. Ninety percent have policies to exclude prospective donors desiring remuneration, 86% for drug abuse and 76% for indications of mental health problems.

Outcomes of Non-Directed Donation

When assessing the outcomes of non-directed donation, the physical health of the donor must be addressed. NDD is not without risk. As with all surgical procedures, some risk is inherent. Donors claim to be well aware of the risks and prepared to accept them (Pradel, Mullins & Bartlett, 2003; Sanner, 2005; Tong, 2012). Segev et al. (2010) report that the mortality rate from surgery is 3.1/10,000 and after 6.3 years was not significantly higher for NDD than that of the healthy matched cohort. Schold et al. (2013) used the National Inpatient Sample to examine comorbidity, complications, and the length of hospital stay of 69,117 (89%) of living donors in the United States since 1998. They found that complications and hospital time has decreased considerably and are similar to that of an appendectomy or cholecystectomy. Their data show significant increases in comorbidity, particularly with hypertension, depression and hypothyroidism. This may be in part because of the broader and less restrictive selection of donor candidates which increases the potential for risk (Schold et al. 2013) and may be due in part to better recognition, documentation and improved follow-up of NDD. These outcomes merit continued scrutinizing particularly as we seek to increase non-directed donation.

Overall, the NDD experience is overwhelmingly positive and many report their post-donation health to be excellent (Gohh & Morrissey, 2001). Two things

to consider that may account for the excellent health reported by donors; 1) donors go through extensive screening to assure they are physically and mentally well enough to donate (Bia et al., 1995; Davis & Delmonico, 2005; Dew et al., 2005) and 2) some donors make it a priority to get healthier to assure they will be acceptable candidates and in preparation for their upcoming surgeries (Jacobs et al., 2004). In follow-up studies, NDD report no long-term pain or lifestyle limitations (Gohh & Morrissey, 2001; Jacobs et al., 2004). Even with the excellent prognosis from living donation, following surgery some donors have had difficulty getting approved for health and medical insurance (Boyarsky, Massie & Alejo, 2014). The good news is that the majority of life insurance companies do not consider organ donation an increased risk (Live Organ Donor Consensus Group, 2000).

Research on the psychological and sociological elements of NDD is limited and the number of NDD is meager. The studies are few and the sample sizes are small. The studies that will be referenced are described below.

- 1) Clarke, Mitchell & Abraham. (2014). Participants included 18 NDD between 2006 and 2011 in the United Kingdom.
- 2) Gohh & Morrissey. (2001). Participants included all 7 who donated their kidneys to strangers at Rhode Island Hospital from 1999 until the time of the study. Three were NDD and four were directed to specified strangers.

- 3) Jacobs, Roman, Garvey, Kahn & Matas. (2004). Participants included 22 NDD from October 1, 1997 to October 31 2003 at the University of Minnesota Medical Center.
- 4) Jendrisak et al. (2006). Participants included 6 NDD kidney donors from June 2002 to December 2004 in the St. Louis area.
- 5) Maple et al. (2014). Participants included 191 live kidney donors both directed (DD) and non-directed (NDD) in the United Kingdom. They compared outcomes of NDD to DD.
- 6) Mark, Baker, Aguayo, Sorensen. (2006). Participants included 20 NDD from 2 Utah hospitals between 2002 and September 2005.
- 7) Massey et al. (2010). Participants included 24/25 NDD from the Netherlands between April 2000 and February 2008.
- 8) Tong et al. (2012). Participants include the 18 NDD in New Zealand from 1998 to 2010.

The NDD psychological and sociological outcome data from these authors will be cited using the last name of the first author only or in the case of Gohh & Morrissey, both authors' last names will be cited.

The overall impact of the NDD process is strongly positive (Kranenburg; Massey) with virtually no negative psychological effects on the donor (Jacobs; Jendrisak; Massey). Commonly expressed sentiments were satisfaction, feeling

good about oneself and self-fulfillment (Jacobs; Mark; Massey; Tong) and many say they would do it again (Gohh & Morrissey; Mark; Massey). In the Jendrisak study, all 6 donors said that without a doubt they would do it again. Many even thanked the transplant team for the opportunity to donate (Jacobs). NDD believed that donating raised their self-esteem (Mark; Massey). The transplant process is challenging and donors expressed that it was worth the effort and inconvenience and as a result they felt resilient, courageous and empowered (Clarke; Tong). Donors in the Jendrisak study were asked to rate the donation experience on a 1 to 10 scale with 10 being the highest. The average score was a 9.8/10.

The research is conflicting on whether donors received social support from loved ones. In the Gohh and Morrissey study, six out of seven NDD had strong support from their friends and families whereas Jacobs reports that six of their 22 donors had family who tried to dissuade them from donating. The Massey study also reported resistance from loved ones and the greater the resistance the greater the stress. Clarke reported that all their donors experienced some level of stress. Resistance came in many forms, much of it from family who were fearful, thought the donor might be putting themselves in unnecessary danger or felt that donors should preserve their organs for potentially needy family.

A large number of donors expressed improved social circumstances. Massey et al. report that donors experienced heightened interpersonal sensitivity, and in the Clarke study participants added that the donation process not only strengthened their relationships, but they added a network of friends in their transplant communities.

Non-direct donation triggers an unanticipated ripple effect. Donation creates interest in donation. After family members received kidneys from strangers, three recipients had family who wanted to “pay it forward” and now consider becoming NDD themselves (Clarke). Mark found that after their loved ones were offered kidneys from NDD, three had recipients had family volunteer to donate. Gohh & Morrissey note that donors encourage others to become donors and some NDD are advocates for donation in their communities (Jacobs; Mark).

Not all social outcomes from NDD are good. Some reported being out of work longer than expected which created stress that they did not anticipate (Jacobs et al.) Massey reports that the more resistance the donor had from family and friends the greater the level of distress they reported.

Why Non-Directed Donors Donate

When trying to understand the non-directed donor [NDD], it is imperative to discern what motivates them to donate. The answers are more

convoluted than one might think. When asked why they donated, most gave more than one reason and no one reason was universal (Jacobs); however, when reviewing the studies, common motives emerge. Altruism is an underlying theme and in relation to organ donation is defined as “a selfless gift to others without expectation of remuneration” (Nuffield Report, 2011). Donors want to help others (Gohh; Jacobs; Jendrisak; Mark; Massey); help them live normal lives (Landolt; Tong).

NDD assume what has been called a donor identity. Donors believe that donating is what they were meant to do, what gives them a sense of purpose. Prior to volunteering, NDD recognized that there was a severe shortage of kidneys (Jacobs) and believed it was their social responsibility to help (Clarke; Jacobs). Others view giving as a precept of their faith or religion and donating was an extension of their beliefs (Goth & Morrissey; Jacobs; Massey). People with a donor identity have a history of other altruistic behaviors particularly Medical Altruism. They are regular blood and organ donors and on the bone marrow national registry (Clarke; Jendrisak; Massey).

Another common theme among donors is a personal connection to disease and death. Many knew someone on dialysis, someone who had a transplant or someone who died waiting for a kidney (Jacobs; Massey). Others had someone in their lives who had a chronic illness or died from disease (Jendrisak; Massey).

Their rationale; they were healthy and wanted to share their good fortune (Clarke; Jacobs). NDD knew they could easily live with one kidney, even considered it a “spare part” (Jacobs; Massey; Tong) and wanted to donate while they were young and their kidneys still viable (Jacobs; Massey).

Defining the Problem

Even with the development of anti-rejection drugs that significantly increases the donor pool, less invasive surgical procedures and accelerated promotional efforts, donation rates are down. This decline is more pronounced in the young, men, blacks, and those with lower incomes (Rodrigue et al., 2013). In order to increase NDD, it is imperative to understand the barriers that keep people from donating. Shanker (n.d.) lists reasons people do not donate. They include financial pressures, socioeconomic status, lack of knowledge, personal health, family values, cultural expectations and previous experience with medical care and the health care system. Financial disincentives and decreased eligibility of donors due to the increase in exclusionary health conditions such diabetes and high blood pressures are two of the most often cited reasons people decline to donate (Shanker, n.d.).

According to an article published in the American Journal of Nephrology (2013), low income individuals have lower donation rates than people with higher incomes. Donation is impacted by financial insecurity and the burden it

puts individuals and their families (Hyde & White, 2010). It has been noted that African Americans have lower rates than Caucasians (Waterman et al., 2010) until one adjusts for income and then donation rates are similar (Gill et al., 2013). This suggest that income may be the pivotal element in why African Americans are less inclined to donate than Caucasians. This may also be true for other minority populations. Income insecurities make donating a kidney virtually impossible for many (Gordon, 2014). Poverty, job insecurity, being underinsured or having no insurance, working by the hour, not being able to take time off, and not being able to afford day care can place insurmountable hardships on otherwise willing donors. Clarke, Klarenbach, Vlaicu, Yang and Garg (2006) found that donor expenses are higher than originally projected. These concerns appear to have particular implications on racial and ethnic minorities where donation is less likely.

As of 2008, only 30% of living donors were racial/ethnic minorities (Waterman et al.; 2010). Donation can be costly even though the recipient, not the donor pays for the medical expenses. Time off work for both the numerous pre and post-surgery appointments, lost wages, transportation to and from the clinic, and child care are all expenses that the donor may incur. This may in part be why Hispanics (Clarke et al.; Reese et al., 2015) and Blacks (Gill et al. 2013; Science Newsline, 2013; Waterman et al. 2010) donate at lower rates than

Caucasians. Even if people have insurance, there are incidental expenses such as travel, lost wages, and child care that insurance typically does not pay (Matas et al., 2000, Shanker, n.d.).

Davis and Delmonico discuss two pieces of legislation the U.S. has enacted to address the financial barrier. The first is the Organ Donor Leave Act which allows federal employees 7 days of paid leave for living donation and the Organ Donation and Recovery Improvement Act makes available state grants to reimburse donors for expenses incurred while traveling to donation sites. Unfortunately, as of yet, these laws have not resulted in increased donation rates (Waterman et al. 2010).

Lack of knowledge, misconceptions and misinformation elicits fear and keeps people from donating (Boulware, Ratner, Sosa & Tu, 2002; Irving et al., 2011). According to the U.S. Department of Health and Human Services HRSA survey in 2012, Americans get their organ donation information from 1) the news, 2) family discussions, 3) communicating with friends, 4) television ads, and, 5) their state's Department of Motor Vehicles. Notably missing are their doctors, other medical professionals, and scientifically based health resources. Misinformation is common concerning surgical risks and patient outcomes, who pays for the surgery and for what expenses, and what religious doctrine says about organ donation.

Religion can deter organ donation (Oliver, Woywodt, Ahmed & Saif, 2010) and often is an overlooked barrier (Oliver, Ahmed & Woywodt, 2012). Hyde and White (2009b) used both focus groups and individual interviews to examine Australians' opinions about live kidney donation. Many participants believed that religious groups (not necessarily theirs) would be objectionable to living donation when in reality most major religious organizations in the world support and even encourage organ donation (Oliver et al., (2012).

Experience with the medical community can deter donation. Many, particularly African Americans and Hispanics are unfamiliar with the health care system (Waterman et al., 2010). Poor language and communication skills and infrequent exposure are common. The donor process is tedious and intimidating and can deter even the most medically savvy. Strong evidence reveals that minority populations receive poorer treatment by health care professionals than do their non-minority peers (Fauci, 2000). Many do not trust that their doctors will prioritize their needs and look out for their best interests (Purnell et al, 2007). Boulware, Cooper, Ratner, Laveist & Powe, (2003) found that that 71% of respondents of all races/ethnicities generally trusted the medical profession, however, Hispanic White and Black respondents expressed the highest levels of distrust.

Family pressure can hinder donation. According to Irving et al., (2011), attitudes and values are formulated during the formative years and families have an influence, either positive or negative on beliefs about organ donation. Many NDD experienced family disapproval when they decided to donate (Clarke et al., 2014; Jacobs et al., 2004). Massey et al. (2010) report that the greater the family resistance, the more likely donors were to experience negative outcomes. When potential NDD were asked about whether their family would approve, Hyde and White (2010) found that most assumed that their families would not.

Personal health concerns were cited as a reason people do not donate. When exploring objections to living donation, Hyde and White (2009b) found that people are worried about their long-term well-being after donating, the uncertainty about the procedure itself, the pain of the surgery, and the life interruption that would come with the donation process (Landolt et al., 2003). Some of the objections are not warranted.

Education may help alleviate the misconceptions and fear (Boulware et al., 2002) and culturally competent programs (Gordon et al., Waterman et al., 2010) will be especially valuable in the Hispanic and African American communities (Siegel, Alvarado, Lac & Crano, 2008; Gordon et al., 2014). Jacobs et al. (2004) report that most of the NDD in their Minnesota study were well informed about

kidney donation; however, other experts report that being educated increases donation. Landolt et al. (2001) argue that decisions about donation are emotional rather than information based. Most donors make quick decisions about donation (Fellner & Schwartz, 1971; Ummel et al.). Sanner (2005) argues that people who want to donate are not deterred when learning of the risks and Strothers et al. (2005) agree. They report that 75% of the donors in their study made their decisions quickly and were no less willing when they learned about the risks.

Efforts to Increase Non-Directed Donation

Even though studies show most donors do not make their decisions based on facts, there is some agreement that non-donors may be more likely to donate if they are educated. According to Landolt et al. (2003), if we provide straightforward and unbiased information about both the need for kidneys and what the donation process entails, we can make an impact on the kidney deficit. Awareness can have a significant impact on donation. In 1988, German physician J. Hoyer made a non-directed donation that raised public awareness and is credited with increasing the NDD rates in Germany from 4% to 20% (Hoyer, 2003). Mass media promotional campaigns can change attitudes. Alvaro, Siegel, Crano and Dominick (2010) conducted pre and post tests and found that

attitudes became more favorable towards behavioral intentions for NDD after in the intervention group, but not in the control group. Schweitzer et al. (1997) prepared an educational program for potential living donors and found that education significantly increased donation, particularly in groups who traditionally have lower donation rates.

I believe that there are two ways to increase the number of non-direct donors. 1) Because some people have donor personalities, we can identify potential donors, impress upon them the need, and give them the opportunity. 2) For those who are not inclined to donate because of fears and misconceptions, we educate them to dispel the misinformation. To address these two strategies, my research intends to identify a donor profile and determine if gaps in information keeps people from donating.

3. METHOD

Background

The purpose of the study was to identify the profile of individuals who have potential to become non-directed kidney donors (NDD). Non-directed donation [NDD] is relatively new and exceedingly uncommon (Hyde & White, 2009a; OPTN, n.d.). There is not much detailed data about donors, nor are there many donors to study; therefore, this research did the next best thing, it attempted to identify people who would consider becoming NDD. In an attempt to create a profile of potential donors, a structural equation model was designed to quantitatively test factors that may affect NDD willingness. The study was conducted at a large southwestern university and the subjects were college students. The model attempted to discover the relationships among the variables believed to predict NDD willingness.

Many of the existing studies on both living donors (Alneas, 2012; Anderson et al. 2007) and more specifically NDD (Massey et al., 2010; Tong et al., 2007) have been done using qualitative research methodology and typically by interviewing non-directed donors following donation. There are studies that have identified characteristics of the NDD donor (Clemens et al., 2011; Gross et al., 2013; Jendrisak et al., 2006; Kayler et al., 2003; Maple et al., 2014; Morrissey et al., 2005; OPTN, n.d.; Segev & Montgomery, 2008; Strothers et al., 2005; Tong et

al., 2007; Zimmerman et al., 2000) and the willing donor (Boulware et al. 2005; Challenor & Watts, 2014; Landolt et al., 2001; Mayo Clinic, 2013; U.S. Health and Human Services HRSA, 2013; Wakefield et al., 2010), but only the Hyde and White (2009a) used structural equation modeling to show what makes people more likely to donate one of their kidneys to an anonymous recipient (Hyde and White, 2009a). Their study was conducted in Australia and examined students studying to be health professionals' and their willingness to consider live kidney donation. This research also used a structural equation model to quantitatively examine some of the interconnections among variables that affect college students' willingness to become non-direct kidney donors. Personal Demographics, Personal Ideologies, Knowledge on Kidney Disease, Donation, and Transplantation, and Experience with Kidney Disease, Donation and Transplantation served as variables in the model. The original model included four demographic (moderating) variables: Gender, Race/Ethnicity, Religious Affiliation, and Sexual Orientation. The variable Age was later added. The three latent variables were 1) Medical Altruism 2) Experience with Kidney Disease, Donation, and Transplantation, 3) Knowledge on Kidney Disease, Donation, and Transplantation. The model had 2 mediating variables, Political Ideology and Religiosity.

Instrument

The instrument was disseminated during the fall semester, 2015. On a 39 question paper survey, students reported on Demographic Information; Political and Religious Ideologies; Experiences and Knowledge on Kidney Disease, Donation, and Transplantation; and Willingness to Donate a Kidney; and perception of Family's Opinion on NDD (See Appendix A). The survey questions were designed to determine the relationships among the model variables. The original model included the following variables.

- 1) Moderating Variables – There were five questions on personal demographics. They were Sex/Gender, Race/Ethnicity, Sexual Orientation, and Religion.
- 2) Mediating Variables – There were two questions concerning philosophical ideology. Religiosity and Political Ideology served as the mediating variables and each was assessed by a single Likert scale question.
- 3) Latent (construct) variables - There were three latent variables.
 1. Nine questions on Experience with Kidney, Disease, Donation and Transplantation.
 2. Three questions on Medical Altruism (the willingness to give a physical part of oneself for the medical benefit of an individual in need).
 3. Twelve questions on Knowledge on Kidney Disease, Donation, and Transplantation.

There were a few survey questions that were of interest to the researcher, but their information was not initially included in the model but added to an

undated model. They were the participant's Age, their Perception of Loved One's Opinion on NDD and the Importance of Loved One's Opinions on their decision to donate. The survey also included questions about willingness to donate to recipients other than strangers. The recipients included family, friends, acquaintances and non-anonymous strangers. These questions were asked as a "warm-up" to asking about the willingness to donate to a stranger,

Sample Selection

The sample was a sample of convenience, but also purposively selected. It was convenient because the researcher is a faculty member at the university and has access to large numbers of students. In addition there were two additional perceived advantages to selecting this sample. 1) Most college students are just entering adulthood and are beginning to formulate their adult values and practices. Participating in this study may pique an interest in organ donation that sparks a lifelong interest and ultimately culminates in donation. 2) Because of the location of the university, it seems likely that a reasonable number of students would have family and friends who have kidney disease, are on dialysis, or are in need of a kidney transplant. According to the National Health and Nutrition Examination Survey (CDC, n.d.), the numbers with End-Stage Renal Disease [ESRD] in Texas (17%) is higher than the national average (15.75%). In the short term, this personal connection to kidney disease might have made some students

more inclined to take the survey and in the long term may have sparked in interest in them becoming NDD at some point in their lives. The assumption that students would likely have experience with kidney disease did not come to fruition. This surprising result will be discussed later in the findings section.

Method of Delivery

The survey was disseminated to students in the following ways: 1) in the classroom by willing instructors, 2) to student athletes on the following teams; baseball, softball and women's volleyball, 3) to Campus Recreation student sports' officials and facility staffs at employee meetings, 4) to Sport Club teams during practices, 5) to residence halls students during hall activities, 6) to student organizations at their meetings and 7) to random students solicited to volunteer. Students generally completed the survey in 10 to 15 minutes. There were no incentives given to students to encourage participation. Students were not mandated to participate but generally did so because of the encouragement or expectation of their professor, coach, residence hall director or group leader who had been solicited by the researcher.

Study Sample

The target sample size was 400, but 300 would have been large enough to have the statistical power to predict any meaningful associations. The number of subjects far exceeded expectations. There were 517 students who completed the

survey and after eliminating surveys with missing data, the number of the sample was a robust 458. The demographics of the sample was a surprisingly similar reflection of the university population.

Sex/Gender

The gender representation in the sample is reasonably close to that of the student body with slightly more female participants than male (51.4% to 46.1%) compared to the University (58% to 42%). Because gender is not binary, the survey included selections for transmale, transfemale and other. There are no data on the number of transgender students at the University and so the percentage of transgender individuals in the United States is used as comparison. In the sample there are 11 individuals who identify as other than male or female which is .024 compared to the estimated .03% of the United States.

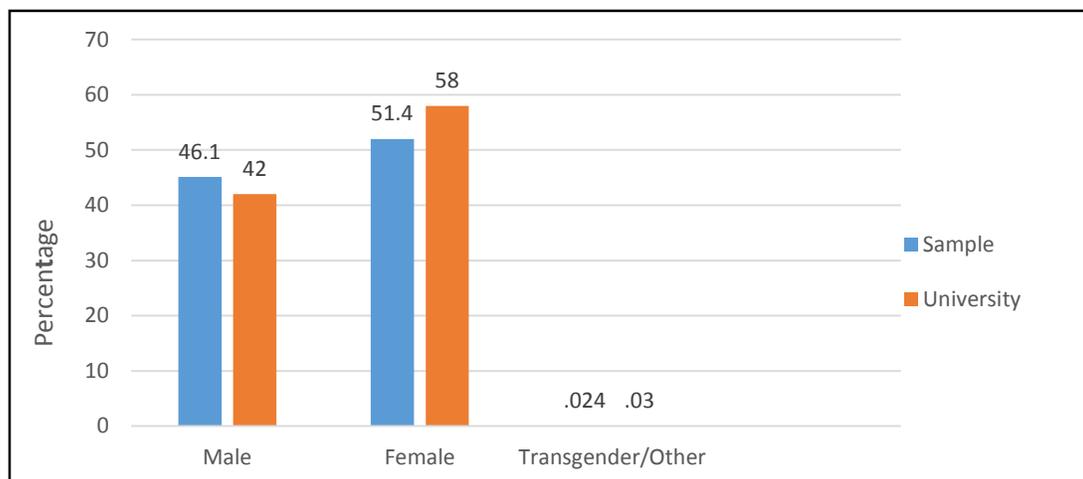


Figure 3.1 Study Data-Sex/Gender Compared to University
Office of University Marketing Statistics, Fall 2015.
Beemyn, G., & Rankin, S. (2011). *The Lives of Transgender People*.

Race/Ethnicity

The Race/Ethnicity percentages closely parallel that of the student body. The Caucasian percentage in the sample is slightly lower than that of the student body, 48.1 to 50% as are those identifying as Hispanic/Latino, 26.9% to 33%. The differences were balanced with a greater percentage of African Americans, 11.3% in the study as compared to 10% in the university population and those who identified as something other than Caucasian, Hispanic or African American, most notably 9.3% being of Mixed Race. A reasonable explanation for the disproportionate numbers of Hispanic students in the sample as compared to the University population might be that some identified as Mixed Race rather than Hispanic.

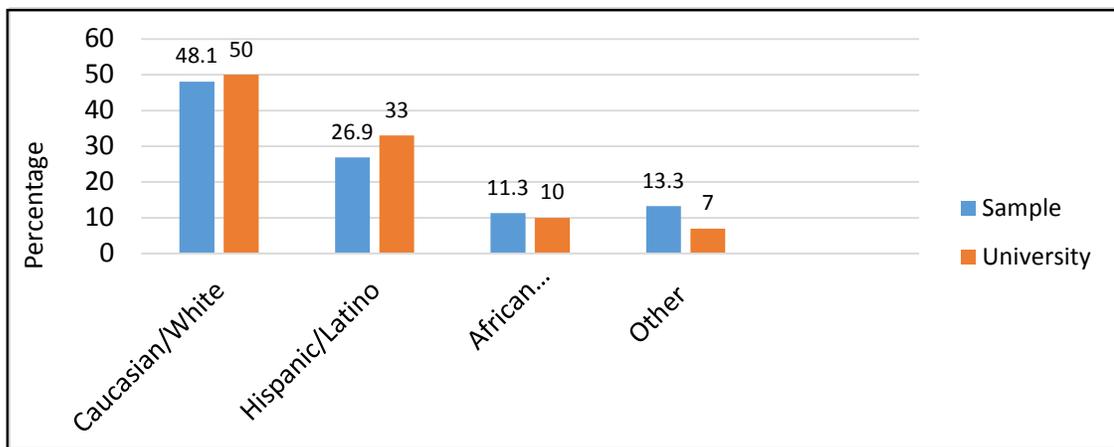


Figure 3.2 Study Data-Race/Ethnicity Compared to University
Office of University Marketing Statistics, Fall 2015

Age

For the purpose of this study, there seems to be no reason to directly compare the study sample ages to the age grouping of the University population, however, the data show the study sample to be notably younger in age (20.3) compared to the 22 year mean age (College Portrait, 2015) of the student body.

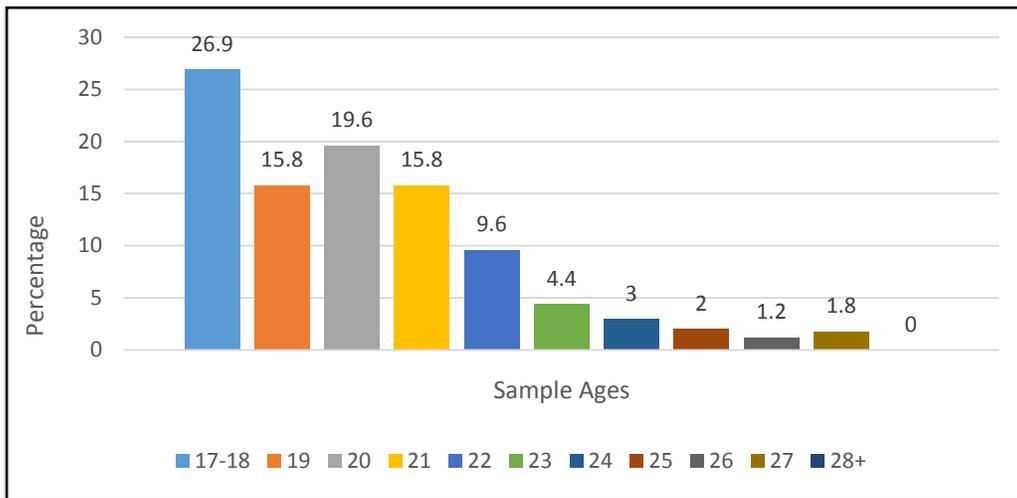


Figure 3.3 Study Data-Age

Religion

The religion of students in the sample was largely Christian (67.6 %) with almost identical percentages of Protestants and Catholics, 33.3% and 34.3% respectively. Those who claim a religion other than Protestant or Catholic was 19.9% and 12.1% have no religious affiliation. The university does not collect data on religion so to get perspective on the sample, a comparison of the religion of people in the state of Texas is used.

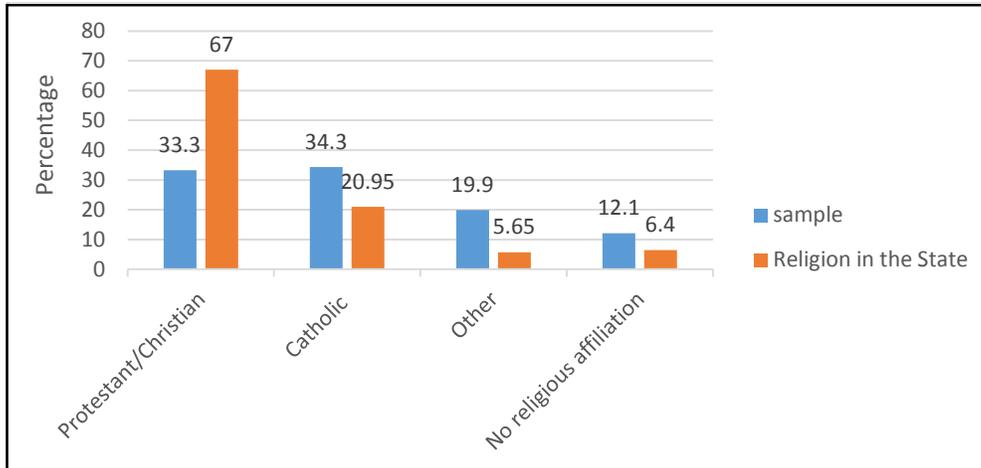


Figure 3.4 Study Data-Religion Compared to State
 Jones, J. (2004). *Tracking Religious Affiliation, State by State.*

Sexual Orientation

No data were found in the existing research that tests how one’s Sexual Orientation affects any type of living organ donation. This study takes the first look at the relationship between Sexual Orientation and kidney donation. There were 46 people who identified as something other than heterosexual/straight which is 11% of the sample. Though the University does not collect data on Sexual Orientation, the U.S. Gallup poll numbers have the percentage hovering right below 4% of the population. Considering these numbers, this sample has a strong representation of LGBTQIA students.

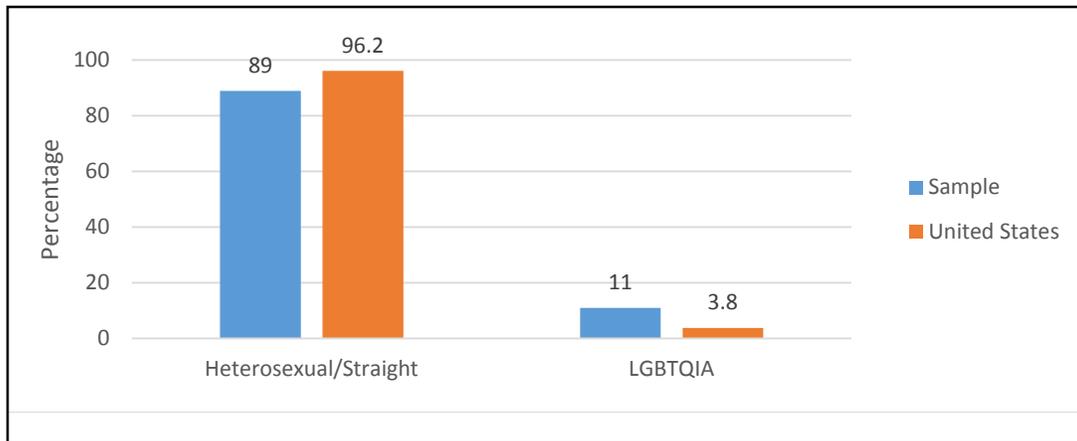


Figure 3.5 Study Data-Sexual Orientation Compared to United States
 Newport, F. (2015). Americans Greatly Overestimate the Percent of
 Gay & Lesbians in U.S.

Religiosity

In addition to demographic variables, this study addressed two philosophical concepts, Religiosity and Political Ideology. The university in the study is located in the Bible Belt so the researcher made assumptions about the bias of the sample. One assumption, that the sample would be religious was confirmed. There was a single Likert-style question used to determine Religiosity, "How important is your relationship with God on a day to day basis?" Of survey participants, 51.5% considered themselves either religious or very religious with another 15.5% somewhat religious totaling 67%. Only 16.8% said they were not religious.

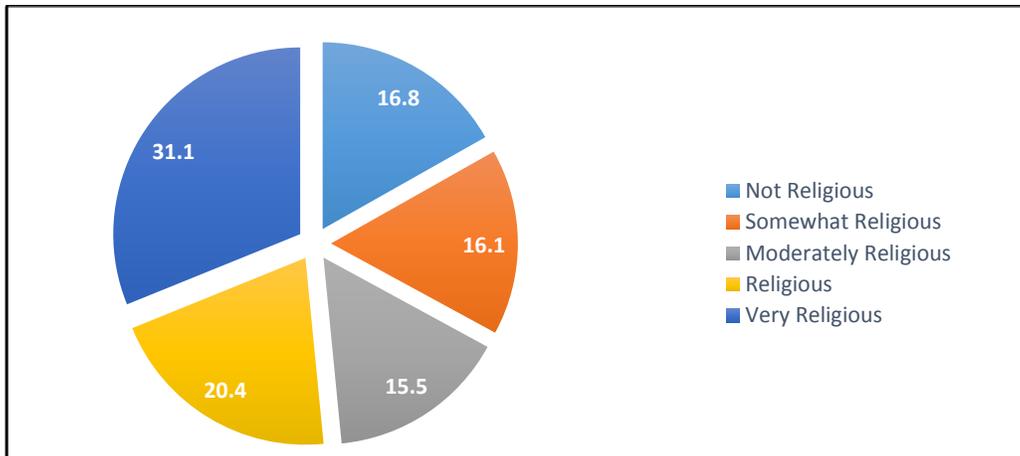


Figure 3.6 Study Data-Religiosity

Political Ideology

The second assumption that was made prior to disseminating the survey was that the sample would be considerably more conservative than liberal. This assumption was not realized. A single Likert-style question asked participants to rank their political philosophical position from very conservative to very liberal. Just under 50% (49.9%) were moderate, 36.5% were either liberal (23.9%) or very liberal (7.2%), and only 21.7% responded conservative (18.2%) or very conservative.

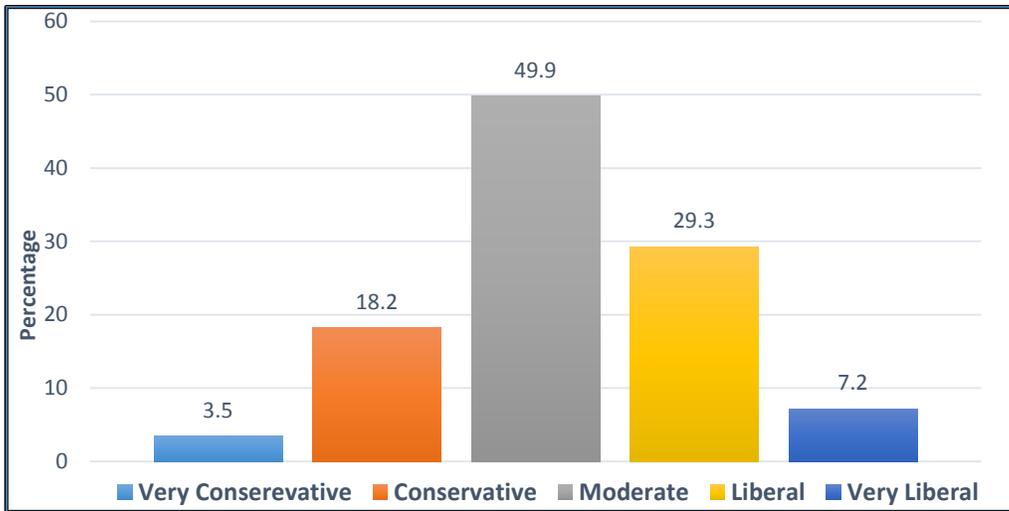


Figure 3.7 Study Data-Political Ideology

4. FINDINGS

Structural equation modeling was used to identify predictors of college students' willingness to consider Non-Directed Donation [NDD]. A binary correlation of variables was run on the original model (figure 4.1) using the SPSS Analysis of Moment Structures Amos Bootstrap Path Analysis program. Path coefficients and R^2 (Kenny, 2015) were used to determine the predictive power of the model variables. It was found that very little in the model predicted a students' willingness to become a [NDD] (See figure 4.1 and table 4.1) and the model was not a good fit to the data.

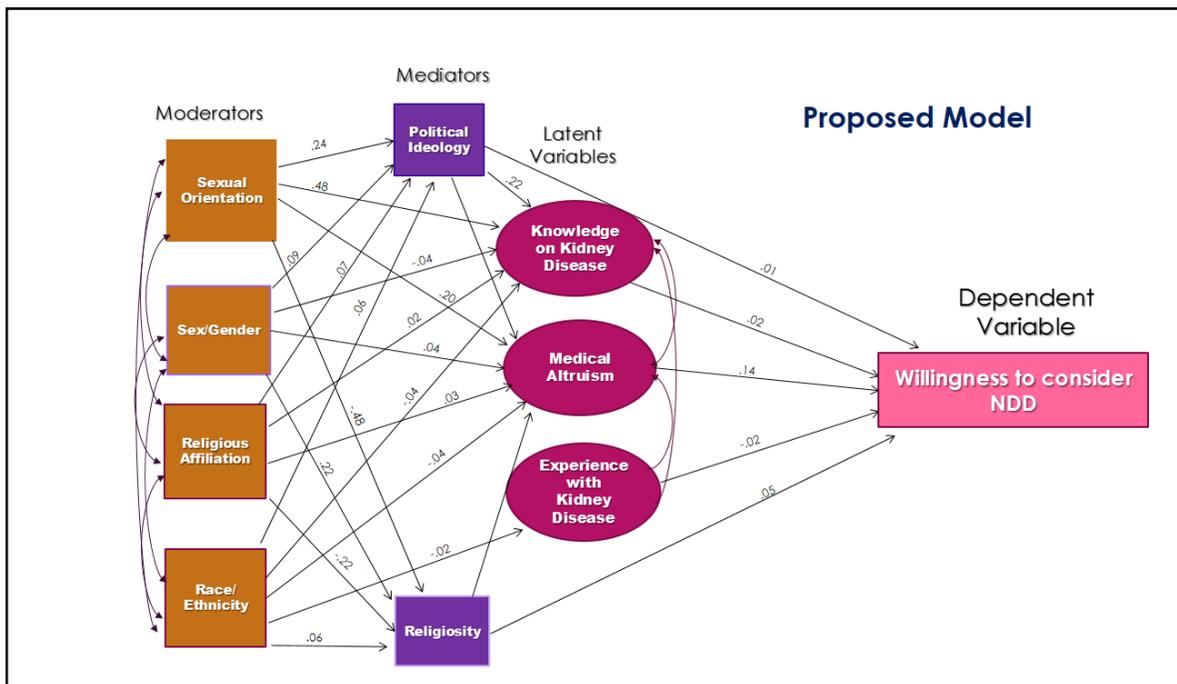


Figure 4.1 Model 1 - Regression Values

Table 4.1 Model 1 - Regression Values (Continued)

| | | | b | S.E. | C.R. | P | r |
|-----------------------|------|--------------------|-------|------|---------|------|-------|
| Political Ideology | <--- | Sexual Orientation | .240 | .074 | 3.220 | .001 | .153 |
| Religiosity | <--- | Sexual Orientation | -.482 | .108 | -4.451 | <.01 | -.188 |
| Medical Altruism | <--- | Sexual Orientation | .203 | .124 | 1.637 | .102 | .082 |
| Knowledge | <--- | Sexual Orientation | .484 | .158 | 3.061 | .002 | .153 |
| Political Ideology | <--- | Gender | .093 | .066 | 1.412 | .158 | .066 |
| Religiosity | <--- | Gender | .216 | .096 | 2.247 | .025 | .093 |
| Medical Altruism | <--- | Gender | -.040 | .110 | -.367 | .714 | -.018 |
| Knowledge | <--- | Gender | -.042 | .141 | -.300 | .764 | -.015 |
| Political Ideology | <--- | Religion | .066 | .012 | 5.294 | <.01 | .238 |
| Religiosity | <--- | Religion | -.217 | .018 | -11.999 | <.01 | -.480 |
| Medical Altruism | <--- | Religion | .027 | .021 | 1.294 | .196 | .062 |
| Knowledge | <--- | Religion | -.027 | .026 | -1.015 | .310 | -.048 |
| Political Ideology | <--- | Race/Ethnicity | .062 | .022 | 2.816 | .005 | .124 |
| Religiosity | <--- | Race/Ethnicity | .062 | .032 | 1.947 | .052 | .076 |
| Medical Altruism | <--- | Race/Ethnicity | -.038 | .037 | -1.036 | .300 | -.048 |
| Experience | <--- | Race/Ethnicity | -.017 | .030 | -.576 | .565 | -.027 |
| Knowledge | <--- | Race/Ethnicity | -.044 | .047 | -.946 | .344 | -.044 |
| Willingness to Donate | <--- | Medical Altruism | .140 | .039 | 3.609 | <.01 | .167 |
| Willingness to Donate | <--- | Experience | -.023 | .047 | -.491 | .623 | -.023 |
| Willingness to Donate | <--- | Knowledge | .016 | .030 | .516 | .606 | .024 |
| Willingness to Donate | <--- | Religiosity | .051 | .038 | 1.353 | .176 | .063 |
| Willingness to Donate | <--- | Political Ideology | .005 | .061 | .082 | .935 | .004 |

Not a single moderating variable; Sex/Gender, Sexual Orientation, Religion or Race/Ethnicity; mediating variable; Political Ideology or Religiosity; and only one latent variable, Medical Altruism was found to predict NDD. Medical Altruism ($r = .14, p < .01$) showed a significant level of predictability, but Knowledge on Kidney Disease, Donation and Transplantation ($r = .02, p = .61$) and Experience with Kidney Disease, Donation, and Transplantation ($r = -.02, p = .62$) did not predict willingness to consider NDD. There were some interesting interrelationships among the co-variables, but nothing that predicts Medical Altruism (see figure 4.2).

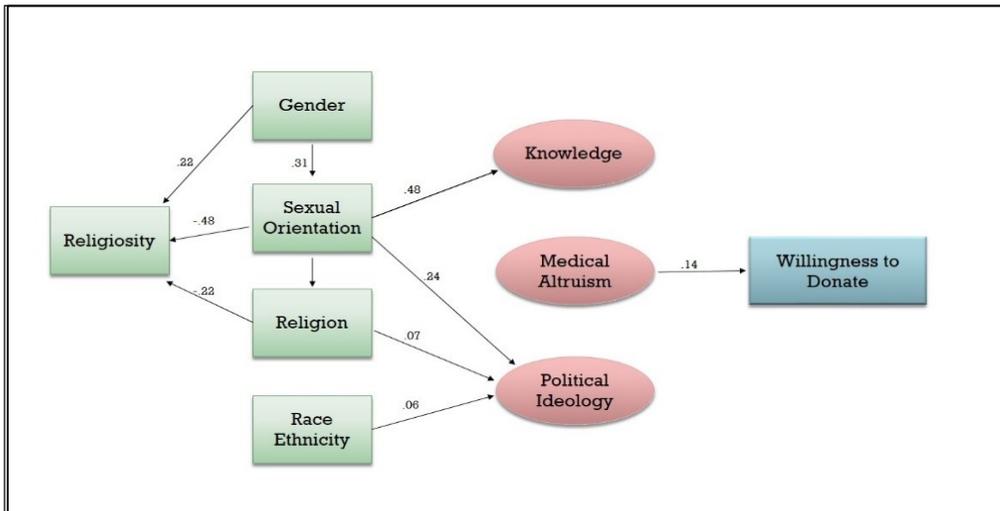


Figure 4.2 Model 2 - Regression Values

Since Medical Altruism had some correlation to willingness to become a NDD, but none of the original moderator or mediating variables predicted Medical Altruism, a new model was created to improve model fit and determine

if there were other indicators among survey data that predicted Medical Altruism. All of the original non-significant variables were removed from the model and 3 new variables were added, 1) Age, 2) Loved One's Opinion of their becoming a NDD [LOO], and 3) The Importance of Loved One's Opinion of their decision to become NDD [ILOO] (see figure 4.3).

A path analysis with bootstrapping was conducted on this model (figure 4.3) and some of the variables were found to be significantly related. Medical Altruism has a small predictive influence on willingness to consider NDD ($r=.16$, $p < .01$) with an error measurement of .03 and a few variables had an effect on Medical Altruism had .05 measurement of error. Age significantly affected Medical Altruism ($r = .17$, $p < .01$) with older students scoring higher on Medical Altruism than younger students. The variable Medical Altruism was calculated by 3 indicators, 1) number of times the subject donated blood, 2) whether or not the subject was on the national bone marrow donor registry, and 3) whether the subject was on the national deceased donor registry. When the indicators were evaluated separately, the number of times the subject donated blood was the greatest predictor ($r = .20$, $p < .01$). Being on the bone marrow donor registry was a slight predictor ($r = .13$, $p < .01$) and being on the deceased donor registry showed no predictive power ($r = .02$, $p = .74$).

Age was also significantly related to ILOO ($R=.12$, $p=.013$). The older the student was, the less impact love ones' opinion had on willingness to donate and the less a student cared, the higher they scored on Medical Altruism ($R=.11$, $p=.022$). This information can be seen in Figure 4.3 and Table 4.2).

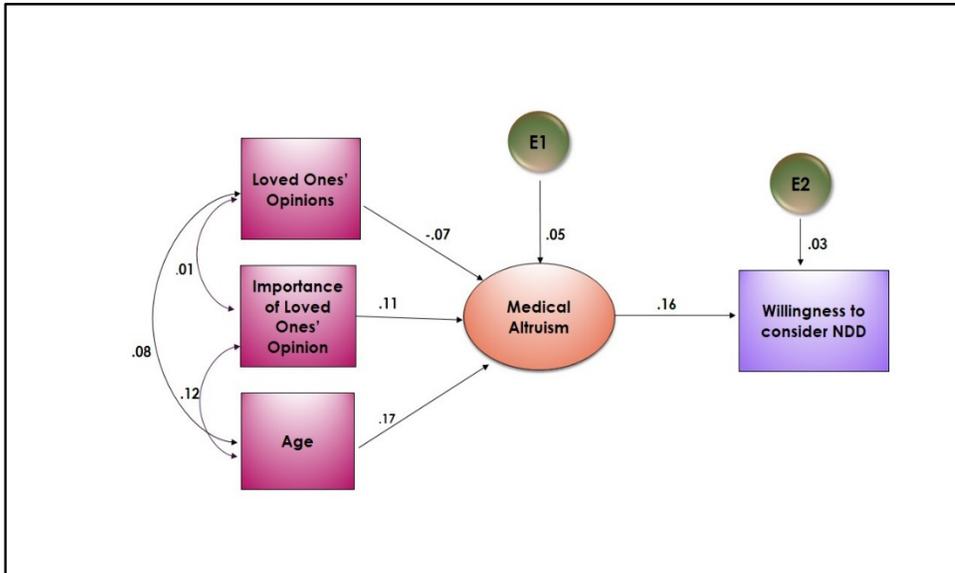


Figure 4.3 Model 3 - Regression Values

Table 4.2 Regression Values (Group number 1)

| | | | Estimate | S.E. | C.R. | P |
|-------------|------|---------------------------|----------|------|--------|------|
| M. Altruism | <--- | Loved One's Opinion (LOO) | -.087 | .055 | -1.577 | .115 |
| M. Altruism | <--- | Importance of LOO | .136 | .060 | 2.283 | .022 |
| M. Altruism | <--- | Age | .108 | .029 | 3.760 | *** |
| NDD | <--- | Medical Altruism | .132 | .039 | 3.414 | *** |

Standardized Regression Weights: (Group number 1 - Default model)

| | | | Estimate |
|-------------|------|----------------|----------|
| M. Altruism | <--- | LOO | -.073 |
| M. Altruism | <--- | Importance LOO | .106 |
| M. Altruism | <--- | Age | .174 |
| NDD | <--- | M. Altruism | .159 |

Covariances: (Group number 1 - Default model)

| | | | Estimate | S.E. | C.R. | P |
|------|------|------|----------|------|-------|------|
| ILOO | <--> | Age | .296 | .119 | 2.491 | .013 |
| LOO | <--> | Age | .214 | .128 | 1.666 | .096 |
| NDD | <--> | ILOO | .017 | .061 | .281 | .779 |

Correlations: (Group number 1 - Default model)

| | | | Estimate |
|------|------|------|----------|
| ILOO | <--> | Age | .118 |
| LOO | <--> | Age | .079 |
| LOO | <--> | ILOO | .013 |

Variances: (Group number 1 - Default model)

| | | | Estimate | S.E. | C.R. | P |
|------|--|--|----------|------|--------|-----|
| LOO | | | 1.405 | .094 | 15.017 | *** |
| ILOO | | | 1.200 | .080 | 15.017 | *** |
| Age | | | 5.252 | .350 | 15.017 | *** |
| E2 | | | 1.904 | .127 | 15.017 | *** |
| E1 | | | 1.344 | .089 | 15.017 | *** |

Squared Multiple Correlations: (Group number 1 - Default model)

| | | Estimate |
|-------------|--|----------|
| M. Altruism | | .049 |
| NDD | | .025 |

Goodness of fit tests were run using the Relative Chi Square (**CMIN/DF**), Chi Square/Degree of Freedom Ratio, and Root Mean Squared Error (**RMSE**) indices. For the CMIN/DF standard, the smaller the value, the better the fit with acceptable numbers being between 1 and 5 (Kenny 2015). The values in this study are 6.361 in the independence model and 6.767 in the default model; therefore the data were not a good fit to the model (table 4.3)

Table 4.3 CMIN Index

| Model | NPAR | CMIN | DF | P | CMIN/DF |
|--------------------|------|--------|----|------|---------|
| Default model | 12 | 20.301 | 3 | .000 | 6.767 |
| Saturated model | 15 | .000 | 0 | | |
| Independence model | 5 | 63.608 | 10 | .000 | 6.361 |

The RMSE index is an absolute measure of fit. According to Kenny (2015), the lower value should be as close as possible to zero and no higher than .5 and the higher number should be less than .08. In this study, the low value in the Default model was .070 and the high was .162 and in the Independence model, the low value was .084 and the high value was .135. The RMSE model results showed that the study data were not a good fit to the revised model (see table 4.3). Neither of these indices demonstrated a good model fit; therefore, although

most of the variables are mildly significantly related, none are good predictors of Medical Altruism and therefore one's willingness to be a NDD.

Table 4.4 RMSE Index

| Model | RMSEA | LO 90 | HI 90 | PCLOSE |
|--------------------|-------|-------|-------|--------|
| Default model | .113 | .070 | .162 | .010 |
| Independence model | .109 | .084 | .135 | .000 |

5. DISCUSSION & CONCLUSIONS

Introduction

According to the LivingBank's January 8, 2016 statistics, 121,678 people are on the national organ transplant waiting list and 100,791 of those are waiting for kidneys. Their statistics also report that every 10 minutes someone new is added to the list and that 22 people die each day without getting their needed organs. Transplanted organs come from cadaver donors, related donors, non-related donors, directed strangers and non-directed strangers, more specifically referred to as non-directed donors [NDD]. Non-directed donation is relatively new, exceptionally rare and an untapped source in the plight to curb the organ shortage. This research attempted to create a potential donor profile that would identify those individuals who might be inclined to become future NDD. Ultimately, if a prototype NDD is created, live kidney donation educational interventions could target these individuals and turn some of these potential donors into actual donors.

This research began with a structural equation model which identified variables that might predict inclination towards non-directed donation. The original model (see figure 5.1) had 4 moderating variables, 2 mediating variables and 3 latent variables. Of these variables, only Medical Altruism significantly predicted willingness to consider NDD.

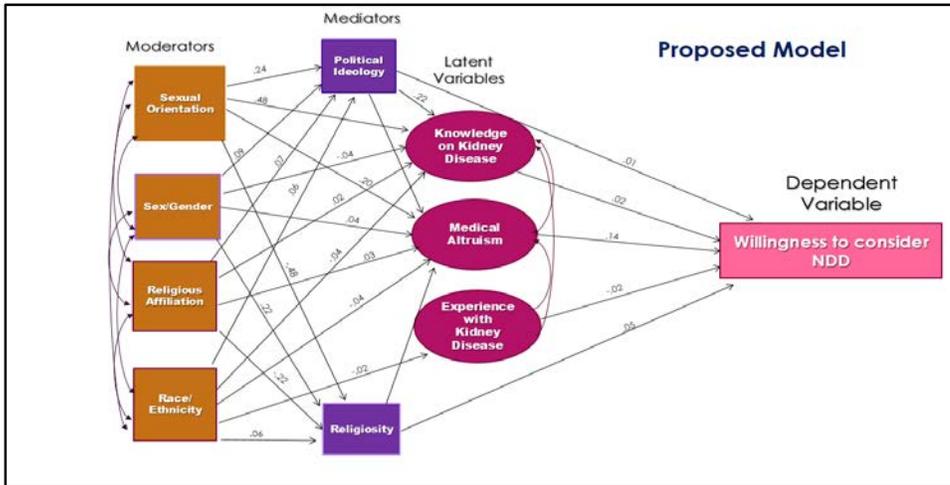


Figure 5.1 Proposed Model - Willingness to Consider NDD (Non-Directed Donation)

Moderating Variables-Demographic Data

Not one of the 4 moderating variables showed predictability; whereas, other studies showed correlations between participants' Sex/Gender, Religion and Race/Ethnicity and non-directed donation [NDD].

Sex/Gender.

Although this study did not show a significant correlation between Sex/Gender and Willingness to Consider NDD, females in the United States are live kidney donors (Biller-Andorno, 2002) and NDD (Kayler et al., 2003; OPTN, n.d.; Zimmerman, et al., 2000) more often than males. Women make up approximately 56% of NDD and male numbers hover around 44% (Segev & Montgomery, 2008). Studies inquiring about willingness to become NDD show similar patterns with females claiming to be more willing than males (Boulware

et al., 2005; U.S. DHHS, 2013; Wakefield et al., 2010). When postulating why Sex/Gender in this study is not a predictor of Willingness to Consider NDD and in reality, females donate more often than males, a number of explanations come to mind. This study asks students if they may consider donating at a future date and time. Actual donors must consider all the real-time, real-life ramifications of their donations. In reality, it may be less impactful on families for females to donate than males. Studies show that there are income considerations that affect donation (Mark et al., 2006; Morrissey et al., 2005; Strothers, 2005). Although the kidney recipient is responsible for the actual medical and surgical costs, there are many fees the donor may incur including travel, lodging, lost wages and follow-up care (Livingdonor101). Recovery can be from 2-12 weeks and depending on the donor's job that may mean many weeks of lost income (Give a Kidney.org). For many families, the loss of the woman's income may be less of a financial burden than that of her husband's. In the majority of American households men are the primary income earners so the woman's income may be more dispensable. In 2014, women earned 79 cents for every dollar earned by men (Hegewisch & Hartmann, 2015). Women are also more likely to work part-time, retire earlier (Brandon, 2011), and have jobs such as teaching with extended time off to allow for donation without interfering with income.

Race/Ethnicity.

Non-directed donors are predominately White/non-Hispanic. The Organ Procurement Transplant Network [OPTN] data show the Race/Ethnicity breakdown of actual NDD to be White/Non-Hispanic 92%, Hispanic 2.5%, Black 3%, Asian 1.5%, and American Indian/Alaska Native and Multiracial combined make up less than 1%. This overwhelmingly Caucasian dominance may have as much to do with other factors such as income, education and experience with the medical profession as it does with race and ethnicity. Purnell et al. (2013) examined the racial/ethnic differences in willingness to donate kidneys. They inquired about both willingness to donate to family members and willingness to donate to non-family members. While most individuals were willing to donate to family members, when examining the Race/Ethnicity responses they found no differences between White and Hispanic willingness, yet they report that African Americans were less willing. However, when income levels and personal experience with the medical profession were accounted for, the lower percentages in African Americans disappeared. Interestingly, the Purnell (2013) study found no difference among Whites, Hispanic or African Americans in willingness to donate a kidney to a non-relative and although being willing to donate to a non-relative is not identical to be willing to be a NDD, this outcome is similar to the data in this study that show no difference in Race/Ethnicity.

When examining the reasons minority donation lags behind Caucasian donation, two explanations seem plausible. First, low donation may be more about ability than desire. Donation requires time off work for the surgery itself, as well as for the numerous pre-donation and post-donation appointments. Willing donors may be deterred by unsympathetic employers and loss of income, particularly hourly wage employees and those who are self-employed. Second, better educated minorities may have fewer misconceptions and be less likely to have experienced some of the medical discrimination of their lower income peers. Both this and the Purnell (2013) studies examine willingness and not actual donation and this may be why racial/ethnicity differences were insignificant.

Another feasible explanation may be because the educational and income levels of Hispanic and African American college students are higher than their representation in the general population and closer to that of their White college peers. Russell, Robinson, Thompson, Perryman and Arriola (2012) conducted a study on African Americans' intent to donate organs and how it relates to their distrust in the healthcare system and found no significant relationship between written intent to donate and distrust. They attribute the possibility of these unexpected results to the higher educational level of their participants. Studies show that donation rates are higher among those with higher incomes (Gil et al.,

2013; Gordon et al., 2005; Jacobs et al., 2005). In addition, many of the income differences may have been negated because college students are only projecting their willingness and not having to face the financial hardships that may come with actual donation. Higher educational levels, current and projected income levels of college students and the differences between predicting and actual behavior may all factor into the results.

Religion.

This study showed no correlation between one's religious preference and their Willingness to Consider NDD. When examining religious denomination and organ donation, the most compelling notation is that Catholics are less likely to be both live and deceased kidney donors (Kidney Buzz, n.d.; Mocan & Tekin, 2005). A possible explanation for the reluctance for live donation may be a misinterpretation of the Church's stance on organ donation. This study's sample had a high representation of Catholic respondents, 31.3% as compared to their state representation of 20.95%. As recently as 1991, then Pope John Paul II espoused the Catholic Church's position on live organ donation when he spoke these words at the First International Congress on the Transplant of Organs "...furthermore, a person can only donate that of which he can deprive himself without serious danger or harm to his own life or personal identity, and for a just and proportionate reason. It is obvious that vital organs can only be donated

after death” (Byrne and Thompson, 2001). However, in this statement made on October 9, 2014, Pope Francis comments reflect the changing Catholic Church’s attitude on live organ donation and although he does not mention non-directed donation specifically, his support for living donation is evident. “We need to explain that donating organs is a gesture of love. Each of us, for example, has two kidneys, and giving one of them to a relative or a person we love is a beautiful gesture” (Catholic Independent News, 2014). Catholic college students may have a more accurate understanding of the Catholic Church’s current stance on organ donation than do their non-college educated peers. A better understanding of the evolving position of the Catholic Church on organ donation may in part account for some of the reason that this study, unlike some previous studies showed that religion itself did not predict Willingness to Consider NDD.

Another factor that may have confounded this study’s results is that many students did not know what the word Protestant meant. Protestant was among the 10 categories from which students selected their religion (See Appendix A) and was meant to include the majority of non-Catholic Christian denominations. Survey choices included the more common U.S. religions, agnosticism, atheism, two or more religions, and no religious affiliation. An open ended space was provided for students who did not see a category that defined their religious

beliefs. It was thought that students would know if they belonged to one of the Protestant denominations, but it became evident that this was not the case. Rather than being a way to identify less common religions, the “not listed” category became a dumping ground for common Protestant denominations including but not limited to Lutheran, Baptist, Christian, Church of Christ, Presbyterian and Methodist. Commonly found in the “not listed” category was the word Christian. These Christian students may not have known that they were Protestant as well as Christian. This confusion may have affected the outcome. Further research on organ donation should seek to find a more effective method to categorize religion.

Sexual Orientation.

No studies can be found that have investigated whether there is a relationship between Sexual Orientation and the willingness to become either a living or a deceased organ donor. This study attempts to be the first and actively sought lesbian, gay, bisexual, transgender and queer [LGBTQ] students to be part of the sample. Because transgender and queer refer to gender identification and not Sexual Orientation, these students’ data are not included in this section, but can be found in the Sex/Gender discussion sections. However, if any transgender and queer students identified as something other than heterosexual, their data are included here.

There were 46 students (11%) who identified as something other than heterosexual. Just as with this study's more researched variables, no significant relationship was found between Sexual Orientation and Willingness to Consider NDD. It is well documented that racial/ethnic minorities receive substandard medical care and as a result have poorer health outcomes (Pearl, 2015) and this translates into a general mistrust of the medical community (Russell et al. 2012) and lower donation rates (Gorden et al., 2014; Russell et al. 2012; Siegel et al., 2008). Just as there are poor health outcomes for people of color; there is a similar disparity in health outcomes in lesbian, gay and bisexual [LGB] individuals (Healthy People, 2020, n.d.; Krehely, 2009). Another disregard by the medical community that might contribute to lower donation intent would be the longtime FDA policy that prohibited gay men or men who have ever had sex with even a single other man from donating blood (American Red Cross, n.d.). The FDA (2015) modified the policy and rather than a life-time ban recommended that blood donation establishments require a 12 month period of same sex abstinence prior to donation. It is possible that the mistrust that results in lower donation rates among racial and ethnic minorities can be extrapolated to sexual minorities and result in lower donation rates, as well.

Another unintended fallout of the policy prohibiting gay men from donating blood may be that gay men incorrectly assume that they are also not

eligible to be kidney donors and thus do not pursue NDD. This may true of the LGB men taking this survey. However, not being able to donate blood may have an unintended, yet positive outcome. Since gay men have been denied the opportunity to donate blood, some altruistic gay men may find an avenue for their altruism and be even more inspired to become NDD.

After considering all the reasons Sexual Orientation was thought to have potential to predict NDD inclination, why did the results show no correlation? This study has a design flaw that may have influenced the outcome. Gay men were penalized when Medical Altruism was scored. The Medical Altruism construct is highly weighted by blood donation and specifically, the numbers of times a person has donated. Gay men are going to have lower scores and altruistic gay men are penalized because even if they want to donate, they are not eligible. Medical Altruism was the only variable in this study to predict willingness to consider NDD, so there was no way to assess LGB Medical Altruism and thus the likelihood to consider NDD. Further research should attempt to find another method to assess LGB Medical Altruism and willingness to consider NDD.

Mediating Variables - Philosophical Ideologies

Two philosophical ideologies were addressed. A single question was asked for each. On 5 point Likert scales, participants were asked to rate both their Political Ideology and their perceived Religiosity.

Political Ideology.

No research has been found on Political Ideology and one's propensity to be a live kidney donor, but there are a few studies that examined its effect on deceased organ donation. Mocan and Tekin (2005) investigated the "determinates" that made people willing organ donors and found that liberals were 8% more likely to be donors than people who were more conservative. In another study, people who labeled themselves as liberal were slightly more likely to agree favorably to organ donation (Nair-Collins, Green & Sutin, 2015). Because it has been noted that a past of medical altruistic behavior is a predictor for both NDD and willingness to consider NDD (Hyde & White, 2009; Wakefield, 2012) and political ideology has been found to impact medical altruism, it was anticipated that this study might find that politically liberal students were more likely than politically conservative students to be Willing to Consider NDD. Unlike past research, not only was there no correlation between Political Ideology and NDD, liberal students were no more likely than conservative students to score well on Medical Altruism. Considering why this might be, we

need to look more closely at two things, 1) the college student demographic and 2) the Medical Altruism variable itself. First, it may be that a college student population has its particular dynamics not reflected in the adult population as a whole. Examining studies on the political makeup of college campuses shows a long history of being somewhat more liberal than conservative, although these trends tend to run concurrently with the political climate of the time (Dey, 1997) and the liberal lean of universities hold true for both students and faculty (Jaschik, 2014, Sax, 2001). However, Sanders (2012) found that even though college students were more liberal than conservative, their actions did not translate into increased political action. College students may espouse a political position not well grounded in critical thought or at least not sufficiently developed or internalized. In this study, a single self-identifying label was used to determine Political Ideology and students may have just picked a label that felt right rather than one that truly represented their beliefs. Because college students' political views are influenced by their environment and specifically their peers (Jaschik, 2014) and they were taking the survey in a group setting, they may have selected the political position they assumed their peers were choosing.

Second, this study's method of scoring Medical Altruism may be biased in favor of conservative students and many of the politically liberal students'

Medical Altruism may have been minimized by this bias. Gallup polls show that racial/ethnic minorities (Newport, 2013) and LGBTQ (Newport, 2014) are more politically liberal. Because of the barriers affecting sexual and racial/ethnic minorities in the inclination and ability to donate, Medical Altruism both in the real world and in this study may be elusive to these more liberal students. And a few final thoughts, 1) it is imperative to note that previous studies were done on favorability to deceased organ donation and not NDD and there are different factors that impact the decision making process for each type of donation, 2) the differences between liberals and conservatives found in the previous studies were only slight and may not transfer to other populations, specifically college students, and 3) being liberal or conservative may have nothing to do with whether people are medically altruistic, willing to consider NDD or actually become non-directed donors.

Religiosity.

In this study, Religiosity did not predict willingness to consider NDD. This is not inconsistent with existing literature where there is conflicting data on how Religiosity plays into decisions regarding organ donation. Oliver, Woywodt, Ahmed, & Saif (2010) found that people who are religious are less likely than non-religious people to become either live organ donors or deceased organ donors. Others had similar findings. Morse et al. (2009) examined deceased

donation and found that religious beliefs had a reasonably strong but indirect effect and often hindered donation. Many non-donors claim that their religious beliefs are in part the reason they choose not to donate. African Americans (Robinson, Klammer, Perryman, Thompson & Arriola, 2014) and Catholics (Mocan and Tekin 2005) in particular believe that their religion opposes organ donation. Other studies found that for some, religious beliefs at least in part, played a role in their decision to donate (Dixon & Abbey, 2000; Henderson, 2003; Jacobs et al., 2004). Nair-Collins, Green and Sutin (2015) found that people who were more religious were slightly more supportive of organ donation than those who professed to be less religious. Most United States faith-based communities support organ donation (Organ Donor n.d.), so incorrectly interpreting their church's stance may lower member donation. Perhaps college students are better informed than the general population and when misconceptions are taken out of the equation and the major barrier to donation is nullified, there are no differences in willingness to consider NDD.

Latent Variables

Experience with Kidney Disease.

Another common theme among non-directed kidney donors is a personal connection to disease and death. Many knew someone on dialysis, someone who had a transplant or someone who died waiting for a kidney (Jacobs et al., 2004;

Massey et al., 2010). Others had someone in their lives who had a chronic illness or died from disease (Jendrisak et al., 2006; Massey et al., 2010). This study showed that Experience with Kidney Disease, Donation and Transplantation did not predict willingness to consider NDD. Participants were questioned about their experience and family history with kidney disease. It was expected that because of the location of the university, in a state that has an incidence of kidney disease higher than the national average, that many students would report a personal connection. The findings proved differently. Not only did this study show no correlation, very few subjects reported either having kidney disease (2.5%) or having a family member with kidney disease (5.2%), and only 20.5% even knew anyone who suffered from kidney disease. Far fewer knew anyone who needed a kidney transplant (12.4%); died waiting for a kidney (2.7%); received a donated kidney from a deceased or a living donor, 4.1% and 6.8% respectively; knew a living donor (6.0%), or donated a kidney themselves (2.1%) (See table 5.1). As students age and have a greater likelihood of being personally impacted by kidney disease, the numbers of people choosing to donate as a result of that experience may increase.

Table 5.1 Experience with Kidney Disease

| Variable | Percentage |
|--|-------------------|
| Had kidney disease | 2.5% |
| Family with kidney disease | 5.2% |
| Knows someone with kidney disease | 20.5% |
| Knew someone who needed transplant | 12.4% |
| Knew someone died awaiting a kidney | 2.7% |
| Knew someone who received donor kidney | 4.1% |
| Knew a living donor | 6.8% |
| Donated a kidney | 2.1% |

The low numbers of students reporting experience may have influenced the results and been in part the reason why there was not a correlation between experience and willingness to consider NDD.

There are two possible explanations for the low numbers of students reporting personal and family history. One, college students lack knowledge about their families' medical histories. They did not report any experiences because they simply do not know. The Centers for Disease Control [CDC] study, Awareness of Family Health History as a Risk Factor for Disease --- United States, 2004 reports that young people do not actively seek family history and that fewer than 30% of their study's 6,175 respondents collect family health

history information (Yoon, Scheuner, Gwinn, & Khoury, 2004). Two, the age of the sample. The average age of student respondents is only slightly over 20, younger than the 22 year age of the average student attending the participating university. These students' parents may not be old enough to have experienced the onset of these conditions and although family history includes family relationships beyond the parents, the survey question did not specify which family members should be included when considering family history. Many of this study's participants may have been reporting on parents' history only and not those of extended family. Having so few participants who reported experience with kidney disease and kidney related conditions, the study may not have enough data to truly measure this variable. Future research may consider defining what family history entails and who it includes.

Knowledge on Kidney Disease.

This study was hoping to discover if students' level of Knowledge on Kidney Disease, Donation, and Transplantation, impacted their Willingness to Consider Non-directed donation [NDD]. It was assumed that many students were unaware of the advancement of treatment options and that misconceptions may lead to unwarranted fears of physical and emotional repercussions for donors, and keep people from being willing to donate, especially to a stranger. Such reluctance would be consistent with what others report (Irving et al., 2011).

Students were asked 12 questions to assess their knowledge on kidney disease, its causes, its treatment options, the transplantation process, and donor outcomes. Not only was there no relationship between student knowledge and their Willingness to Consider NDD, this research found students were generally unformed. The assessment score was determined by the number of the 12 questions respondents answered correctly. The mean score was 5.70, slightly under 50%, the high score was 11 and the low was a mere 1. The median and the mode were both six. With such a large sample and broad range of student levels of knowledge, there was ample information to find a relationship if one existed.

Interestingly, Boulware et al. (2002) report that for many, knowledge did not affect donation inclination. They report that some donors were willing to accept greater risks than were actual risks and researchers found that having the correct information had no effect one way or the other on their desire to donate. Decisions seem to be more based on personal and emotional factors than factual information. This study's results may reflect similar priorities the Boulware study found. Students may be responding from an emotional desire and not actually concerning themselves with the risks involved in the actual surgery.

Medical Atruism.

This study uses the term Medical Altruism to mean giving a part of one's physical self to improve the health and wellbeing of another, without remuneration and usually without knowing the recipient or the outcome. Medical Altruism is a specific form of altruistic behavior and is frequently reported in those willing to be NDD. Examples include donating blood and tissue; bone marrow; and organs. Non-directed donation [NDD] has much in common with these forms of altruism, but with one important distinction, the donor gives up an organ that might be needed later in life. Blood and bone marrow regenerate easily and quickly and deceased individuals no longer need the donated organs. Even with the differences, most studies show that previous altruistic behaviors can be established in both non-directed donors and in those willing to consider NDD. NDD are more likely to be deceased organ donors (Hyde & White, 2009; Landolt, 2003; Wakefield, 2010), have donated blood (Boulware, 2005; Hyde & White, 2009), and on the national bone marrow donor registry (Jendrisak, 2006). Their rationale, they were healthy and wanted to share their good fortune (Clarke, 2014; Jacobs, 2004). NDD knew they could easily live with one kidney, even considered it a "spare part" (Jacobs, 2004; Massey, 2010; Tong, 2012) and wanted to donate while they were young and their kidneys still viable (Jacobs; Massey).

There were three questions that served as indicators for Medical Altruism, 1) number of times participant has donated blood, 2) whether or not participant is on the deceased organ donor national registry, and 3) whether or not participant is on the national bone marrow registry. The question on blood donation was scored incrementally according to the number of times a person had donated. The more often they donated, the greater the commitment, thus the greater the altruism score. This study found that Medical Altruism was a small but significant predictor of a Willingness to Consider NDD.

In this study there are some concerns that may have affected its outcome, potentially minimizing the effect of Medical Altruism. According to the American Red Cross (n.d.), to be eligible to donate blood a person has to be 17 years old or in some states 16 if they have parental consent, and there is an eight week mandatory waiting period between donations; therefore, the older the person is, the more opportunities they have had to donate. Older blood donating students would then have a higher Medical Altruism score and younger altruistic students may not have altruism scores that truly measured their altruism. Since the average age of the sample is 20.3, there may not be enough variation in altruism scores to make a significant impact.

Age is not the only blood donation criteria that may affect participants' ability to score well on Medical Altruism. Common reasons that people may not be eligible to donate are 1) they do not meet the height or weight guidelines, 2) they are anemic or slightly anemic at the time of donation, 3) they have past behaviors considered high risk of contracting sexually transmitted infections, HIV or Hepatitis, 4) they are males who have had sex with other males, and 5) they have injected a drug not prescribed by a doctor (Red Cross, n.d.).

Although Medical Altruism is a well-established predictor of non-directed donation, future studies should also find ways to define altruism in college students that are not influenced by numbers of times or ability to donate blood.

The Redesigned Model

The original model was a poor fit to the data and Medical Altruism was the only variable that predicted Willingness to Consider Non-Directed Donation. Because the other two latent variables had low, non-significant impact on willingness to donate, the new model excluded both the variable on Knowledge on Kidney Disease, Donation, and Transplantation, and the variable about Experience with Kidney Disease, Donation, and Transplantation. The new model used Medical Altruism as the single latent variable (See figure 5.2).

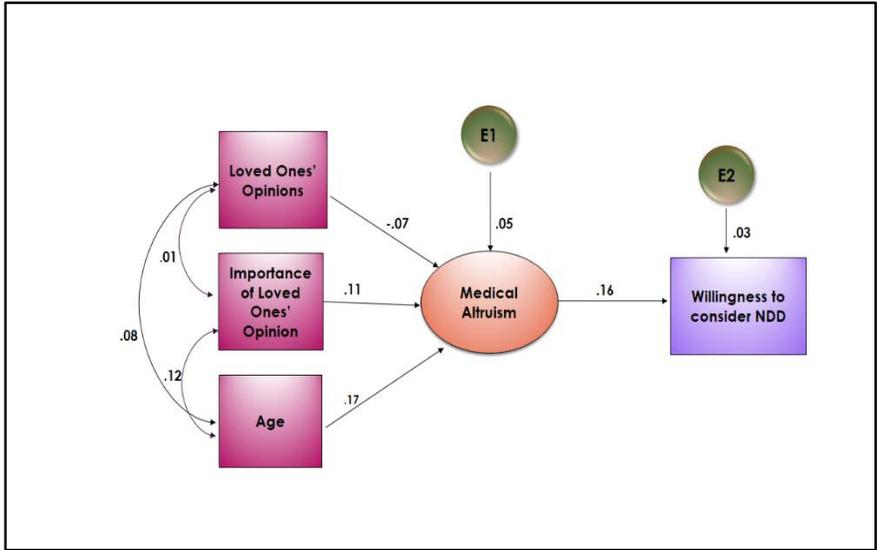


Figure 5.2 Model 3-Factors that Predict Medical Altruism

A closer look at the construct Medical Altruism was warranted because of its predictive power on Willingness to Consider NDD. When more closely scrutinizing data that were gathered by the survey, but not factored into the original model, there were three questions thought to have potential to predict Medical Altruism and a model was created to test their effects (see figure 5.2). The variables added were 1) Age, 2) Loved Ones' Opinion of them becoming a NDD, and 3) the Importance of Loved Ones' Opinion in their decision to consider NDD. After analyzing the data, some of the variables were found to be mediated through Medical Altruism and each other.

Findings in the New Model

Loved Ones' Opinions.

Much research has been done on the importance of the opinion of others on human behavior. In this study there were surprising numbers of students who perceived that if they were to become NDD that some of their loved ones would disapprove or strongly disapprove (40.7%), have significant reservations (39.7%); and only 19.7% thought their loved would be proud and supportive.

The Theory of Planned Behavior [TPB] postulates that people's behavior is in part determined by the perceived approval of loved ones (Hyde, Knowles & White, 2009). Research on TPB and organ donation (Rocheleau, 2013) and blood donation (Masser, White & Hyde, 2008) found that the opinions of significant others positively influenced donation. It was thought that in this study common sentiments would emerge, but that was not the case and Loved Ones' Opinions did not predict Medical Altruism or Willingness to Consider NDD. It may be that college students are independent thinkers and make their decisions based on personal reasons. Arnett (2000) describes the period of life between the ages of 18 and 25 as emerging and it is "distinguished by relative independence from social roles and from normative expectations". The results from this study may reflect that emerging independence.

Age.

In the original survey, students' ages were asked for information gathering purposes only and because there was not expected to be a large enough variation to have an impact on the results, age was not included in the original model. Students were recruited from residence halls; athletic teams; student organizations and clubs; student worker staffs; and academic classes. Because of the recruitment methods, the student sample was expected to be primarily young and undergraduate. According to Forbes (2015), 85% of this university's students are under the age of 25. The predication of a young age sample came to fruition, with the mean being 20.3, well under the university's mean age of 22 (College Portrait, 2015). When the Medical Altruism construct was more closely evaluated, the importance of age was reconsidered and found to have some implications.

Age & Medical Altruism.

Age did not directly predict the Willingness to Consider Non-Directed Donation, but there was a small correlation between Age and Medical Altruism ($r = .17, p < .01$). Older students were more Medically Altruistic than younger students. Some of the explanation for these data are straightforward. The longer students are in college, the more experience they have and the more

opportunities become available to them. College campuses host blood, organ and bone marrow donor drives and students have ample opportunities to participate. They also have more opportunities to learn about these societal issues and needs associated with them.

The sequential nature of identity development may be another explanation as to why older college students scored higher on Medical Altruism than their younger peers. College students are just beginning to develop their adult identities, understanding who they are, and what defines them. This self-awareness develops over time. Adult identity development, specifically as it relates to altruistic behavior was examined by Randall and Wenner (2014) in a study on pro-social behavior in college students. They found that altruism increases as college women age and it was evident even in the narrow 4 year age span of undergraduate education. Unlike with women, increasing altruism was not found in college men (Randall & Wenner, 2014).

Altruistic behavior as part of an adult identity is what some have labeled a donor identity. People donate either organs, blood or bone marrow because it gives them a sense of purpose and they say the giving is just a part of who they are (Gohh & Morrissey, 2001; Jacobs, 2004; Massey, 2010). It is well established that people who become NDD claim donor identities and have a history of other altruistic behavior, particularly Medical Altruism. They are regular blood and

organ donors and are often on the bone marrow national registry (Clarke, 2014; Jendrisak, 2006; Massey, 2010). Older students may have more established adult identities and thus, donor identities.

A final explanation for why older students may score higher on Medical Altruism is because of something inherent to this survey. One of the indicators for the Medical Altruism construct is the number of times participants have donated blood. The higher the number, the greater the Medical Altruism score. Because there is a mandatory eight-week waiting time between donation attempts, older blood donors have had more opportunities to donate and thus earn higher scores. Even though there are flaws in this study on defining Medical Altruism in college students, Age is still an important factor. Since college students are continuing to develop their adult identities and altruism can be a component of some of these identities, early educational intervention may be able to shape susceptible students' identities to a more altruistic direction. College student, Aaron Champene's Environmental Ethics class was an impetus for him to strive to lead a more ethical life and part of that identity was what motivated him to become a NDD (St. Louis Community College, 2013).

Age and the Importance of Loved Ones' Opinions.

Older students report that their loved ones' opinions are less important in their decisions regarding NDD than younger students and they are also more Medically Altruistic and Medically Altruistic students are more Willing to Consider Non-Directed Donation. The covariance among the variables of Age, Importance of Loved Ones' Opinions [ILOO], Medical Altruism, and Willingness to Consider NDD is worth further examination.

Adult identity development is a likely explanation for the relationship between Age and Medical Altruism. The longer students have been away from home, the greater the development of that identity and the greater the independent thinking. According to Freeman (2012) in an essay on altruism and living organ donors published in the AMA Journal of Ethics, "altruism is a manifestation of individual autonomy." Study data show a relationship between Age and the Importance of Loved Ones' Opinions about their Willingness to Consider NDD. For older students, Loved Ones' Opinions are less important than they are for younger students ($R=.12$, $p=.013$) and the Importance of Loved Ones' Opinions predicted Medical Altruism ($R.11$, $p=.022$). This concept is consistent with what others have found. Internal locus of control is correlated with altruism in college students (Eubanks, 2008). Those who think independently and whose behavior does not rely on the approval of others

[ILOO] were older and more Medically Altruistic. Independent thinking may be a stepping stone for Medical Altruism in those so inclined. Identifying independent thinking college students may be a step in identifying potential non-directed donors.

Although not studied specifically, research has demonstrated that internal locus of control may be necessary for NDD. Challenor and Watts (2014) interviewed NDD and report that every one of their study participants had family and friends who strongly disapproved and tried to dissuade them. There seems to be an inner passion that fuels non-directed donors that is not deterred by the objections of others. Further research on Internal Locus of Control as it relates to Willingness to Consider NDD is warranted. If it can be established that medically altruistic, independent thinking college students are more likely to consider NDD, methods can be designed to identify these students and target educational interventions to nurture their altruism and groom them as potential NDD.

Willing to Consider Non-Directed Donation

It was not the specific intent of this study to determine the numbers or percentages of students who expressed a willingness to consider becoming non-directed donors, but the numbers are of interest. Since 2001, there have been a

number of studies that queried individuals about their willingness to become non-directed donors. The percentages are encouraging, Spital (2001), 45%; Intermountain Donor Services 2001 & 2003, 49%; Henderson, et al. (2001), 29%; U.S. Department of Health and Human Services (2012), 54.7%; and the Mayo Clinic (2013), 49%. In this study a single question asked about Willingness to Consider NDD, "Would you be willing to donate a kidney to an anonymous stranger (unspecified pool of people needing kidneys)?" The answer selections were presented on a 5-point Likert scale and ranged from very unlikely to very likely. Participant responses are displayed in table 5.2. The largest percentage of students would likely not consider NDD (62.8%) and either answered very unlikely (37.3%) or somewhat unlikely (25.5%). Fewer than half of the students (37.1%) said that they might consider NDD, with 22.6% of all students saying their decisions depended on the circumstances. Another 14.5% said that they were somewhat or very likely to donate, of which 3.9% or 20 students claimed they would be very likely. Intervention focus should be directed at the 22% of students who said they might donate depending on the circumstances. It seems unlikely that intervention strategies will impact those who responded they were unlikely to donate and those who responded they were likely are already inclined so the greatest emphasis should be on those who are the most malleable, those whose donation decisions depend on the circumstances. Future

research should investigate the circumstances that guide college students' decisions concerning NDD. It is possible that barriers to donation might be alleviated through education or modifying social policy.

Table 5.2 Willingness to Consider NDD

| | Frequency | Percentage |
|-------------------|------------------|-------------------|
| Very Unlikely | 193 | 37.3 |
| Somewhat Unlikely | 132 | 25.5 |
| Depends | 117 | 22.6 |
| Somewhat Likely | 55 | 10.6 |
| Very Likely | 20 | 3.9 |
| Total | 517 | 100% |

Study Limitations

- 1. The participants self-report*
- 2. The difficulty in projecting future behavior*
- 3. The length of the survey*
- 4. The voluntary nature of the survey*
- 5. The legal restrictions on gay men and blood donation*
- 6. The age factor in Medical Altruism*

There are six identified limitations found in this study. 1) The participants self-report. There is a relationship between the level of threat a question poses and the level of truthfulness in the response. According to Northrup (1996), the

more threatening the question, the greater the likelihood of falsifying the response. Most of the questions in this survey have low levels of threat and therefore, this threat is of little concern. To further minimize the threat, the surveys are anonymous and the participants are directed to skip any questions they do not wish to answer. A well-recognized limitation in self-report survey research is the disparity between intent and behavior (Ge et al., 2014; Landolt et al., 2003; Siegel, Alvaro, Lac & Crano, 2008). When asking about a behavior as arduous and rare as NDD, the gap may be significant. Landolt, et al. (2001) recognized this limitation when asking people about their willingness to donate. They noted that their results show that greater percentages of people claim to be willing to donate to family and friends than are being seen at transplant centers. Some may perceive themselves or want to portray themselves as more altruistic than in reality they are and the results are likely to be inflated, 2) it is difficult to project future behavior. Although the questions on donation instruct participants to answer the questions on willingness to donate in regard to anytime in their lives, not necessarily in the near future, it may be difficult for students to think beyond the "here and now".

In addition, respondents are asked to make snap decisions about their future willingness to do something as life changing as donating a kidney and most have never heard of or considered the possibility. This may further

accentuate the gap between intent and behavior. The results may underestimate the numbers of students who would donate at a later time and under different life experiences or circumstances, or altruistic students may be inclined to donate but are not having to deal with life circumstances that might limit their real-life opportunities to donate, 3) The length of the survey. The survey has 39 questions and took most students between 10 and 15 minutes to complete. According to Chudoba (2011), the longer the survey, the less time participants spend on each question. To counter some of this impact, the survey was designed so that the demographic questions, those questions requiring the least time and brain power, are at the end of the survey. However, the survey content is sequentially designed to build familiarity with the idea of kidney donation before asking the survey's most significant question, whether they would consider NDD. The question was the 34th of 39 questions. Being towards the end of the survey may have affected the time and thought students devoted to it. 4) Taking a voluntary survey is an altruistic act in itself (Landolt et al., 2001) and people who took it may be more altruistic than the average person and that in itself may have inflated the numbers who responded that they may be Willingness to Consider NDD. Although all students were ultimately given the choice to participate, some of the altruistic effect of taking a voluntary survey may have been negated by the process. The researcher approached teaching staff, college coaches, faculty

student organization sponsors, and Student Affairs personnel to seek permission to disseminate the survey to their respective groups. The survey was distributed during classes, group meetings, or practices. There may have been some subtle pressure to participate from either faculty, staff administrators, coaches or even their student peers. 5) Gay men have not had the opportunity to donate blood because of the U. S. Food and Drug Administration restrictions. Until recently, if a man had ever had sex with another man, no matter how long it had been, he was prohibited from donating blood. Recent changes in FDA recommendations are less restrictive, but still impact gay men's ability to donate. Today's guidelines use a 12 month timeframe from last male to male sexual encounter as the marker to restrict donation (Red Cross, n.d.). For this study, there is no true way to interpret gay men's Medical Altruism. Further research should investigate other ways to gauge Medical Altruism in this group. Perhaps an attitude rather than a behavioral assessment would be more effective. 6) The age factor in Medical Altruism. The method by which Medical Altruism was scored favored older students. One of the three indicators was the number of times the participant had donated blood. Older students were at an advantage because depending on the state, people cannot donate until the age of 16 or 17 and must wait 56 days in between donations (Texas Blood Institute, n.d.). Younger students did not have the opportunity to score as high as older students. Again,

the suggestion of evaluating Medical Altruism from an attitudinal rather than a behavioral perspective seems warranted.

Study Delimitations

1. *The use of a convenience sample.*
2. *The location of the university.*
3. *The use of college students.*

There were three delimitations in the study. 1) The use of a sample of convenience rather than a random sample. Paasche-Orlow et al., (2005) studied the use of convenience sampling in health care and caution about generalizing results to the general population; therefore, the data collected in this study does not represent all populations. 2) The sample are students of a university located in the Bible Belt portion of the United States. Prior to running the data, the researcher assumed the demographic survey sample would have a conservative Christian slant rather than the more broad-based religious and political spectrum of the United States and the results may be skewed accordingly. After calculating the results, the perception of a conservative sample was not realized. The Political Ideology was fairly evenly distributed and the sample was more liberal than conservative. Although almost 50% claimed their Political Ideology to be moderate, 21.5% were more conservative than liberal and 36.5% more liberal than conservative. 3) The sample population is college students. There is a well-

established relationship between health literacy and educational level (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, and Rudd 2005). This survey assessed student knowledge on kidney disease. Students in college are likely to know more about kidney disease than the general public so there was potential for the range of student levels of knowledge to not be as great as actually exists in the general public. After calculating the data, students were not well informed which may have been limiting in determining whether knowledge impacts willingness to consider NDD.

Conclusions and Considerations for Future Study

This study intended to see if there was a donor profile of college students who might later in their lives be candidates for non-directed kidney donation [NDD]. Identifying these students, educating them on the need for live kidneys and alleviating any fears and misconceptions might help groom them for potential future donation. A structural equation model was developed to determine what variables predicted willingness to consider NDD. The moderator variables were Sex/Gender, Race/Ethnicity, Sexual Orientation and Religion; the mediating variables were Religiosity and Political Ideology; and the latent variables were Knowledge on Kidney Disease, Donation, and Transplantation, Experience with Kidney Disease, Donation, and

Transplantation, and 3) Medical Altruism. Medical Altruism is the only variable that had any predictive power for NDD. When the model was broken down further, Age and Importance of Loved Ones' Opinion were found to predict Medical Altruism. Although not many of the variables correlated to willingness to consider NDD, there is much to be garnered from these results that warrants further examination.

Suggestions for Further Research

1) These data confirm previous studies that show Medical Altruism, particularly blood donation as a predictor of non-directed donation [NDD]. Early identification and cultivation of these predictive behaviors can prime college students for a life of continued altruism and potentially NDD. Future research should explore ways to identify students who exhibit medically altruistic behaviors.

2) Although identifying those with medically altruistic behavior can garner potential NDD, there are limitations to using behavior alone. Research should be done to find ways to identify medical altruism in college students that is not linked to behavior. Circumstances prohibit some from being medically altruistic. Gay men, younger students and students who do not meet the eligibility requirements for blood donation, or people who have not been exposed to medical altruistic opportunities who are potential NDD will be overlooked.

Finding a method that tests attitudes may be fairer and more inclusive so that altruism is more based on a true inclination and less on opportunity.

3) Altruism can be recognized through avenues not related to medicine. It seems reasonable to assume that students who demonstrate altruism in non-medical ways would respond similarly to those who demonstrate medical altruism.

Future research should focus on identifying college students who volunteer in soup kitchens, women's centers, food banks, and other community non-profit organizations and test them for inclination to consider NDD.

4) Although in this study, Knowledge on Kidney Disease, Donation, and Transplantation was not a predictor of inclination to consider non-directed donation, it was evident that students were woefully unformed. NDD may be so foreign that students did not have time to grasp the concept before being asked if they would consider it. With limited information and little time to assimilate the concept, students may be more likely to reject the idea than if they had additional time and more information. To minimize this, it might be worth pursuing a brief pre-survey introduction. This would give participants a few minutes to conceptualize what non-direction donation entails before being asked about their willingness to donate. Students would then be better able to make informed decisions rather than responding with preconceived notions.

5) Lesbian, gay, bisexual, transgender and queer [LGBTQ] students and their proclivity towards NDD warrants further study. This study attempted to be the first, but study limitations impeded the outcome. Because gay men have been restricted from donating blood and blood donation attempts was an indicator of Medical Altruism and Medical Altruism was a predictor of NDD, there was no effective method to determine potential for non-directed donation among gay men. When perusing the national and international literature, there are no data on whether being LGBTQ encourages, discourages or has no effect on one's likelihood to be a NDD. Their marginalized status and lack of opportunities may ultimately discourage, or possibly even encourage donation. The LGBTQ community may be an untapped resource for non-directed donation and its inclination warrants further study.

6) In this study, 22 % of the respondents said that depending on the circumstances, they might consider non-directed donation. This undecided group would probably be the most effective to target with educational interventions. Students who were willing to consider NDD are already primed to donate and those who reported that they were unlikely to donate probably will not no matter what the intervention, but those in the middle are potentially malleable. Valuable information on donor motivation could be garnered by employing qualitative research methods such as focus group and individual

interviews to explore what factors might inhibit students from considering NDD and what factors would increase NDD likelihood.

7) This study examined the relationship between both Political Ideology and Religiosity and the Willingness to Consider NDD. Each was determined by a single self-identification question. This study showed no relationship between either Political Ideology or Religiosity and the Willingness to Consider NDD. Other studies have shown that political liberals were more likely than political conservatives to favor donation while the research on religiosity and its impact on NDD is conflicting. To better understand the relationship between Political Ideology and Religiosity and Willingness to Consider NDD, future researchers should devise multi-indicator constructs to assess one's Political Ideology and one's Religiosity.

8) To better understand what motivates people to consider NDD, future research could use qualitative methodology to delve more deeply into what influences student beliefs about NDD. Focus groups of like-minded students could be conducted. Separating students into three groups, 1) those who would consider NDD, 2) those who would not consider NDD and 3) those who might consider NDD depending on the circumstances would be a place to start.

Implications

Non-directed kidney donation is still in its infantile stages and early identification and education of potential donors may help to increase the donor pool and decrease the escalating need. Medical Altruism is a predictor of NDD and finding ways to educate medically altruistic college students is a place to begin.

Educational interventions need to be established to better inform medical professionals about the need for kidneys, the kidney donation process, and ways to communicate this information to their patients. Including non-directed kidney donation information in the medical school curriculum may be a starting point. According to Bardell, Hunter, Kent, & Jain, M. (2003), medical students are not trained to provide adequate organ donation information to patients.

Blood donors are likely candidates for NDD and educating lab technicians about the kidney shortage and non-directed donation opportunities could be part of a systematic delivery of NDD information during the blood donation process. Educational materials and pamphlets on NDD could be created and placed in blood donation centers and sent to donors as a follow-up to the donation process. Blood donation centers could provide NDD information on their websites and in the recruitment of blood donors. To enhance non-directed donation, establishing working partnerships between organ transplant centers

and blood donation organizations would enhance the likelihood of finding non-directed donors.

Another educational opportunity for non-directed donation would be targeted at organ donors. Donation and procurement organizations could follow-up each registration by sending registrants materials on the kidney shortage crisis and the opportunities to become non-directed donors.

Final Thoughts

It is of considerable interest and bewilderment that there was little about college students' Demographic Characteristics; Political or Religious Ideologies; or Knowledge or Experience about Kidney Disease and Donation to predict their Willingness to Consider Non-Directed Donation. Non-directed kidney donation is exceedingly rare and research is sparse. The gap between need and availability is widening. Any efforts to increase the body of knowledge to ultimately increase donor kidneys is warranted. College students are just beginning to develop their adult identities and being a NDD may be part of that identity. College students may not be an immediate source of kidneys, but identifying and nurturing altruistic college students may have long-term implications towards narrowing the gap between need and available kidneys.

**APPENDIX SECTION
APPENDIX A**

Survey-Living Organ Donation

Please Complete on the Scantron

1. How many times have you donated blood?

- | | | | | |
|---------|--------|-----------|-----------|-------------|
| a. | b. | c. | d. | e. |
| 0 times | 1 time | 2-5 times | 6-8 times | More than 8 |

2. Are you an organ donor? (On the national registry or on your driver's license)

- a. Yes b. No

3. Are you on the National Bone Marrow registry?

- a. Yes b. No c. I don't know

4. How important is religion/your relationship with God in your day to day life?

- | | | | | |
|------------|-----------------------|-------------------------|-----------|-------------------|
| a. | b. | c. | d. | e. |
| Not at All | Somewhat Important | Moderately Important | Important | Very Important |

5. How would you best self-identify your philosophical position?

- | | | | | |
|-------------------|--------------|----------|---------|--------------|
| a. | b. | c. | d. | e. |
| Very conservative | Conservative | Moderate | Liberal | Very liberal |

Personal experience with kidney disease and donation

6. Have you been diagnosed with kidney disease, high blood pressure or diabetes?
 - a. Yes
 - b. No
7. Do you have kidney disease in your family?
 - a. Yes
 - b. No
 - c. Uncertain
8. Do you know of anyone with or who has had kidney disease?
 - a. Yes
 - b. No
9. Do you know of anyone who needs/has needed a kidney transplant?
 - a. Yes
 - b. No
10. Do you know of anyone who has received a kidney from someone who has died?
 - a. Yes
 - b. No
11. Do you know of anyone who has received a kidney from someone who is alive when they donated (family or loved one, friend, acquaintance)?
 - a. Yes
 - b. No
12. Do you know of anyone who has died while waiting for a kidney?
 - a. Yes
 - b. No
13. Do you know of anyone who has donated a live kidney (while they were alive) to a family member or loved one, acquaintance, stranger?
 - a. Yes
 - b. No
14. Have you donated an organ to someone who needed one (kidney or liver part)?
 - a. Yes
 - b. No

Knowledge of kidney donation and transplantation

15. When a person has only one functioning kidney, he/she will need some form of medical treatment.
- a. True
 - b. False
16. What are options if the kidneys stop working?
- a. Go on dialysis
 - b. Get a transplant
 - c. Either dialysis or a transplant
 - d. There is nothing that can be done, the person will die relatively quickly
17. A good thing about having two kidneys is that when one kidney gets diseased, the second kidney can serve as a backup or reserve.
- a. True
 - b. False
18. Which racial/ethnic group is the most likely to develop kidney disease and need a kidney transplant?
- a. White/Caucasian
 - b. African American
 - c. Native American
 - d. Hispanics
 - e. The risk is about the same. Kidney disease is an equal opportunity disease.
19. In the US, which is/are the most common causes of kidney disease?
- a. Obesity and lack of exercise
 - b. Genetics and family history
 - c. Diabetes and high blood pressure
 - d. Kidney injury

20. It is difficult for a person needing a kidney transplant to find a donor who matches.
- b. True b. False
21. Kidney surgery is difficult and very risky.
- a. True b. False
22. Following a transplant, the typical amount of time the donor will spend in the hospital will be approximately
- a. 1-3 days d. Two weeks
b. 3-5 days e. A month
c. One week
23. Kidney transplant surgery can be done with very little scarring for either the donor or the recipient.
- a. True b. False
24. Typically after a person donates a kidney, he/she can resume a normal life, no different than before the surgery within a few months.
- a. True b. False
25. The chance of death for the donor from the kidney transplant surgery is
- a. less than .05
b. .05 - 1 %
c. 2-5%
d. 6-10%
e. Greater than 10%
26. The success rate for kidney transplants from living donors is superior to those from cadaver donors.
- a. True b. False

Willingness to consider donation

Instructions - If your health; personal and financial circumstances; and the timing were right, answer the following questions to the best of your ability. (Please consider your answers to reflect any time in your life, not necessarily in the immediate future)

Use the scale below to answer

Very Unlikely b. Somewhat Unlikely c. It Depends d. Somewhat Likely e. Very Likely

27. Would you be willing to donate a kidney to a blood related family member?
28. Would you be willing to donate a kidney to a friend?
29. Would you be willing to donate a kidney to an acquaintance (co-worker, classmate, member of church/religious congregation, friend of a friend)?
30. Would you be willing to donate a kidney to a person who solicits the public for a kidney (has a social media site dedicated to finding a donor, craigslist)?
31. Would you be willing to donate a kidney to an anonymous stranger (unspecified pool of people needing kidneys)?
32. Assume you decided to donate a kidney to a stranger (even if you would not), now consider what you think the overall reaction of your immediate family (parents, siblings, children, grandparents) will be.
 - a. Very proud and mostly supportive
 - b. Somewhat supportive with but with definite reservations
 - c. Mostly negative, try to talk me out of it but would reluctantly support me if I still wanted to do it
 - d. Very negative and not be at all supportive of my decision
 - e. Mixed, some would be supportive and others would not

33. How much would your immediate family's reactions to your decision about live kidney donation influence your decision?

- a. Absolutely
- b. Considerably
- c. Somewhat
- d. Very little
- e. Not at all

Demographic Data

34. Sex/Gender

- a. Male
 - b. Female
 - c. Trans Male
 - d. Trans Female
 - e. Not listed
- Identify if you wish _____

35. Race/Ethnicity

- a. Caucasian/White/Non-Hispanic
- b. Hispanic/Latino
- c. African American/Black
- d. Asian
- e. Native American/Alaskan Native
- f. Native Hawaiian or Native Pacific Islander
- g. Mixed Race (Two or more races)
- h. Not Listed Identify if you wish _____

37. Sexual Orientation

- a. Heterosexual/Straight
- b. Gay/Lesbian
- c. Bisexual
- d. Not listed (Please identify if you wish) _____

38. Religion-Which best describes you

- a. Protestant
- b. Catholic
- c. Jewish
- d. Latter Day Saint (Mormon)
- e. Muslim
- f. Buddhist
- g. Agnostic (Not sure if there is a God)
- h. Atheist (Do not believe in God)
- i. No religious affiliation
- j. Two or more different religions

Not Listed (How would you self-identify?)

39. What is your age today?

- a. 17-18
- b. 19
- c. 20
- d. 21
- e. 22
- f. 23
- g. 24
- h. 25
- i. 26
- j. 27
- k. 28 or older Please write in age _____

APPENDIX B

Consent Form

You are being asked to be part of a research project. The purpose of the research is to determine what groups of people may be likely to donate a kidney to a stranger with hope that the information obtained can be used to increase the donor pool. The researcher is attempting to assess Texas State University students' Knowledge on Kidney Disease, Donation, and Transplantation and their willingness to be kidney donors. This survey has approximately 50 questions and should take no longer than 15-30 minutes to complete. The benefit to study participants is that they will add to the existing body of knowledge about kidney donation and potentially help increase the likelihood of people in need of kidneys finding donors.

For the pilot study only, students who participate and are in the researcher's classes will receive 5 bonus points for their participation. The researcher will give no incentive to participants for participation in the regular study.

The research is being conducted by Dawn Roberts of Texas State University, Department of Health and Human Services. Email dr15@txstate.edu, 143 Jowers Center, 512-245-8014.

Answering the questions on this survey should pose no risk to participants; however, there are a few personal questions pertaining to one's health and the health of one's loved ones. Please feel free to skip any questions that may be too uncomfortable or threatening to answer. The survey will not ask for names or any information that will identify participants.

For those who experience any discomfort as a result of participation in the survey there are mental health professionals that can help. Here is a list of three.

- 1) Texas State University Health Center- 512-245 – 2161
- 2) Texas State University Counseling Center 512-245- 2004
- 3) Hill Country MHDD Centers –817-466-0660

This research 2015L4532 was approved by Texas State University IRB on 4-22-2015. Questions about the research or research participants' rights should be directed to the IRB chair, Dr. Jon Lasser (512-245-3413) or lasser@txstate.edu or Becky Northcut, Director, research Integrity and Compliance (512-245-2314) or bnorthcut@txstate.edu.

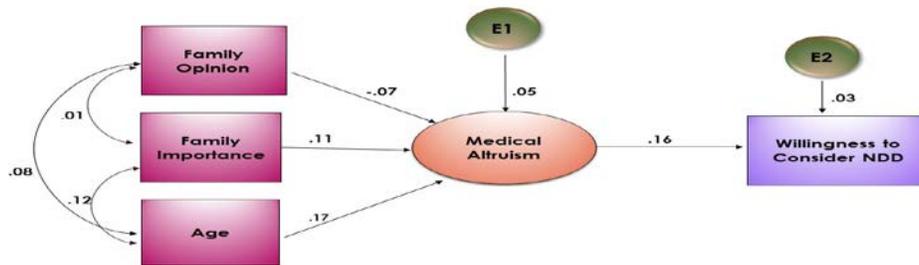
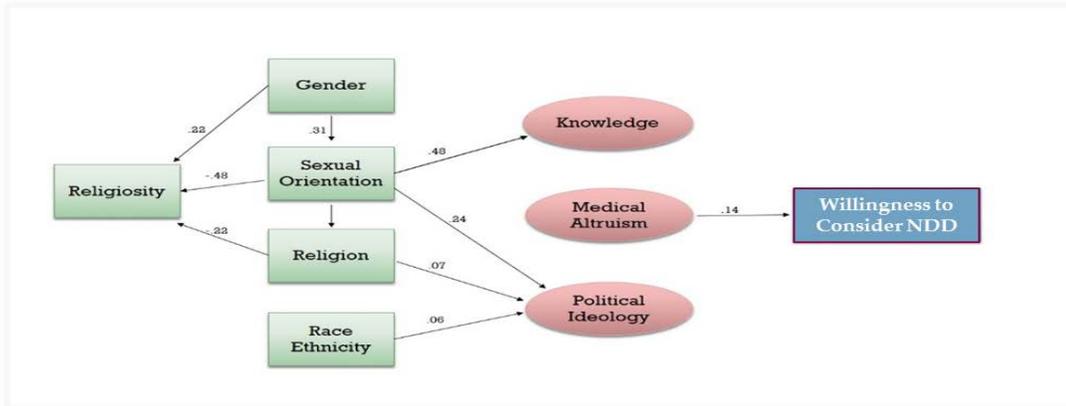
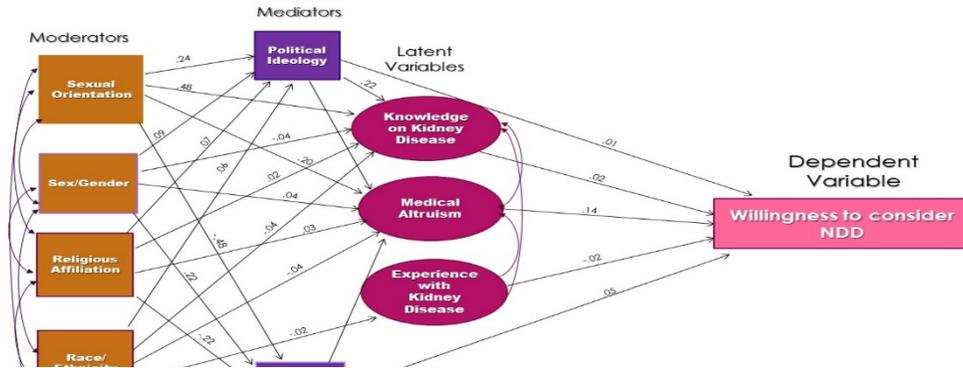
Your participation is voluntary and your refusal to participate will not affect your grade or the instructor's opinion of you. You may choose to quit taking the survey at any time without any penalty.

A summary of the findings will be provided to participants upon completion of the study, if requested. To access results of the study, contact Dawn Robarts.

Signature of Participant

Date

APPENDIX C Structural Equation Models



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