An Investigation of the Role of Psychological Altruism in Living Kidney Donors

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Dedication

This thesis is dedicated to my mom, the first and most important organ donor in my life.

Abstract

Altruism is the selfless concern for the wellbeing of others. Multiple researchers have investigated altruism in the general population, but altruism has not been measured in living kidney donors. This study assessed the altruism of 168 living kidney donors, a representative sample from the University of Minnesota Kidney Donor Transplant Program. Three scales measured altruism (Helping Attitudes Scale, Self-Report Altruism Scale, and Altruism and Gift Giving Battery). Participants also responded to items eliciting their suggestions about questions to assess altruism in living kidney donors. Statistical analyses revealed the present sample had significantly higher altruism scores than normative samples on the Helping Attitudes Scale and Self-Report Altruism Scale. There were no significant differences in altruism scores for living related donors (n = 86.5, 62.9, 39.4) versus living unrelated donors (n = 88.5, 66.1, 38.5). Factor analysis of responses to items on the altruism scales yielded four factors: *Physical help to stranger; Gifts; Volunteerism rewards;* and *Risk/ sacrifice in helping.* Logistic regression indicated likelihood of being a living unrelated donor increased if participants scored lower on Volunteerism rewards, higher on Risk/sacrifice in helping, and they were older. Content analysis of participants' responses regarding questions to assess altruism yielded six themes: *Questions regarding the donor's cultural ideas of giving; Questions regarding how much risk and discomfort one is willing to endure for another; Comments regarding personal family obligation or selfish motivation; Questions regarding the donor's emotional expectations post-donation; Questions regarding the financial and long-term health cost to the donor; and Questions will not capture the true motivation as the*

decision to donate comes without hesitation. Additional findings and practice, policy and research directions are presented.

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Chapter 1: Introduction

Altruism concerns the place of the other in moral experience, especially when the other is in need (Batson, 1991); it involves an action motivated to benefit the other even if there is significant self-sacrifice that extends beyond biological relations. Altruism is the desired premise of living organ donation. Living donation takes place when a living person donates an organ (or part of an organ) for transplantation to another individual. The living donor can be a family member, such as a parent, child, brother or sister *(living related donation*). Living donation can also come from someone who is emotionally related to the recipient, such as a friend, spouse or an in-law (*living unrelated donation*). In some cases, living donation may be from a stranger (*nondirected donation*). Making a living kidney donation entails the individual volunteering to undergo a personally unnecessary surgical procedure in order to benefit another (potentially unknown) person. Two important questions are: What motivates an individual to take such extreme action? and Can their actions be called altruism?

Physicians, scientists and American organ transplant centers do not view kidney donors as being motivated by altruism (Roff, 2007). While the general public considers living related, unrelated and nondirected organ donors to all be "altruistic," the medical community historically has been suspicious of any individuals offering their kidney to another person, genetically related or not. In the first published investigation of "altruism" among living unrelated kidney donors, Sadler, Davison, Carroll and Kountz (1971) found "most physicians and many transplant surgeons maintained that no matter what, these people [living unrelated donors] must be abnormal to do such a thing" (p. 98).

The researchers concluded most physicians view the decision to donate a kidney to an unrelated person as "impulsive, suspect and repugnant" (p. 99).

In the sixty years since the world's first living kidney donation, much progress has occurred with respect to ethical guidelines, regulatory procedures and psychological assessment of living organ donors. Still, however, an assumption of psychopathology remains prevalent, among other presumed self-serving reasons (e.g., seeking fame, atoning for one's transgressions, or enhancing one's own mood) as the American medical community seeks to understand the motivations and decision-making processes of such a generous donation.

Are these suspicions and cautions from the medical community grounded? Though the medical community considers living organ donors' motivations to be born of psychopathology, while the general public considers these same donors to be altruistic, little is known empirically about the actual motivations of living organ donors themselves. Moreover, empirical evidence is lacking concerning: (1) the prevalence of altruism among living kidney donors, and (2) whether related and unrelated donors differ in their degree of altruism.

Statement of the Problem

As of July 2014, more than 134,000 people are on the organ transplant waiting list in the United States. About 110,000 (82%) need a kidney. Just over 14,000 kidney transplants occurred in 2013 in the United States; over two-thirds involved deceased donors. The most up-to-date information, found on the U.S. Department of Health and Human Services website, shows that 83 people are added each day to the kidney waiting

list, while 14 people die each day waiting for a kidney transplant. Clearly there is a pressing need for more individuals to donate their kidneys. This need will only grow in the coming years as the biggest risk factors for kidney damage grow in our country: high blood pressure, diabetes, and a history of kidney disease (Bramstedt & Down, 2011).

In order to address the "kidney shortage," some physicians, lawyers and economists have proposed a government-regulated system of compensation for living kidney donors. Their proposal is described in the book *When Altruism Isn't Enough: The Case for Compensating Kidney Donors* (Satel, 2008). This recent proposal introduces a different motivator, egoism, which may "crowd out" or "overshadow" motivations of altruism. Universal egoism—the assumption that all human behavior is motivated by self-interest— may resolve the problem of organ shortage by replacing altruistic donations with a market-based, for-profit commodification of body parts (Satel, 2008).

Significance of the Proposed Research

The Western medical model, which is prevalent in the U.S. traditionally, concentrates on dysfunctional or defective aspects of human life, and by doing so challenges the public's collective faith in basic humanity (Bramstedt & Down, 2011). Researchers need to learn more about the motivational repertoire of living organ donors in order to substantiate assumptions about human nature and human potential, especially in the face of a changing organ procurement system. Also important is the need to understand the decision making process involved in kidney donation as well as the psychological effects of organ donation. All fields of study would benefit from understanding the social and psychological act of giving by organ donors. Thus the

proposed survey study is intended to investigate three major research questions: (1) What is the prevalence of altruism among living kidney donors? (2) How do related, and unrelated donors compare in their degree of altruism? and (3) From select measures used in prior research, which items are the strongest predictors of individuals who are high versus low in altruism?

The present study has important implications for furthering understanding of kidney donation. The research is grounded in literature across different contexts concerned with human intention and motivation, including: forensic neuropsychiatry; counseling psychology; social services; ethical, moral and legal systems; medicine; business and nonprofit sectors; and religion and spirituality. Furthermore, this study is centered in psychological thought drawn from both the rich *practice* of people who interpret the human experience as well as the *scientific and medical knowledge* that furthers understanding of human existence.

Extensive study of psychological altruism has yet to adequately inform the medical model, which generally focuses on disease and distress rather than human potential. Similarly, the humanities have much to value from rapidly developing medical advances that have the power to change our physical, social and cultural ways of relating to ourselves and others. The proposed study seeks to open up “the central question…” that His Holiness the Dalai Lama proposes: “… central for the survival and well-being of our world--is how we can make the wonderful developments of science into something that offers altruistic and compassionate service for the needs of humanity, and the other sentient beings with whom we share this earth" (Dalai Lama, 2005, p.206).

The next chapter consists of a review of literature divided into four major sections: 1) a review of social science research concerning how altruism is conceptualized; 2) a review of social science research and medical research concerning what motivates altruism at large and organ donation, specifically; 3) a review of social science and medical research concerning the decision making process for altruistic acts as well as organ donation; and 4) a review of the psychological outcomes of kidney donation.

Chapter 2: Literature Review

How is Altruism Conceptualized?

The term "altruism" was first coined by philosopher August Comte (1851) who conceptualized it as the renunciation of self-interest (egoism) and motivation to live for others (Post, Underwood, Schloss, & Hurlbut, 2002). Since then, it has been a subject of interest to sociologists, economists, psychologists, philosophers, neuroscientists, and medical doctors in their efforts to examine whether there really is such a thing as unselfish altruism, especially directed toward strangers and non-kin familiars.

In attempting to further understand altruism, many social scientists have conducted studies to test various conceptualizations of the phenomenon. Beginning with the basic distinction between altruism (intentionally promoting needs of others) and self-interest (promoting needs of self), Flynn and Black (2010) revealed a false dichotomization of the words *altruism* and *self-interest*, a view that altruism occurs only when all the benefits go to the person receiving help. If the actor receives any benefits, the act is no longer considered altruistic, but egoistic. The question arises: Can altruism and indirect positive consequences for the actor co-exist? Batson (2002) answers "yes," asserting there is a conceptual continuum between pure self-interest and pure altruism based on the amount of risk or sacrifice the actor makes. Batson's (1981) theory, the empathy-altruism hypothesis, supports Sorokin's early findings (1950) that love and evoked empathy for a person in need produce the motivation to act altruistically. And, finally, Levine, Norenzayan, and Philbrick (2001) support the conceptualization that an altruistic act must be beyond the actor's culturally socialized role or duties.

Based on these examples, one may conclude that the social science literature conceptualizes psychological altruism as comprised of five core components: 1) the act is ultimately motivated to benefit the other even if there are positive, unintended consequences to the actor, 2) the act involves a sacrifice or cost to the actor, 3) the act is motivated by empathy, 4) the act is intentional, and 5) the act is beyond the actor's culturally socialized role or duties. This conceptualization of altruism raises an additional question: Why are humans altruistic? The next section reviews literature that examines factors believed to motivate altruism.

What Motivates Altruism?

Several motivations, beyond empathic concern, have been proposed for altruism in general, including "altruism born of suffering" (Oliner & Oliner, 1988; Staub, 2003), altruism motivated by a "perspective of shared humanity" (Monroe, 1994), and "altruism as attachment security" (Mikulincer et al., 2005). Monroe (1984) and Oliner (1988) both studied groups of people who qualify as altruists (heroes, rescuers, Good Neighbors), attempting to identify common qualities, backgrounds, and motivations for their altruistic behavior. Their findings are summarized later in this chapter. Mikulincer et al. (2001, 2003, 2005) conducted a series of studies based on Bowlby's (1969/1982) attachment theory and found enhanced attachment security facilitates increased compassion and helping of out-group members.

Regarding organ donation specifically, both medical researchers and psychologists propose a number of motivators, including "altruism as pathological" (Sadler et al., 1971; Spital, 2001), and "altruism born of abundance" (Bramstedt, 2011).

Sadler et al. (1971), Spital (2001), and the American medical community at large acknowledge that while altruism can be a desirable thing, more attention needs to be paid to altruism's dark side, termed "pathological altruism" to fully understand the act of organ donation. These researchers ask at what point altruism becomes distorted, self-sacrificial and pathological. Bramstedt and Down (2011) interviewed nondirected organ donors in order to understand their motivations in giving a stranger their kidney, liver lobe or lung lobe. Their interviewees' profiles converged in having a personal or familial background in a service-oriented profession, or volunteerism. They were not wealthy financially or materially, but they did, however, consider themselves wealthy in empathy and life satisfaction. Simply put, these individuals were motivated by their sense of abundance to help take care of other people.

Altruism born of suffering.

Emerging perspectives in psychological research provide evidence supporting the concept of *altruism born of suffering*; some researchers describe how individuals who have suffered may become particularly motivated to help others—not only despite their difficult experiences, but precisely because of them (Staub & Vollhardt, 2008). In 2003, psychologist Ervin Staub coined the term *altruism born of suffering* and said, "Many people who have been neglected physically or sexually abused, survived persecution, torture or genocide against their group, rather than becoming hostile or vengeful against the world devote themselves in significant ways to helping others" (p. 540). Thus, people who experience adversity and trauma may develop resilience and "posttraumatic growth," more often than assumed (Bonanno, 2004, p. 21).

Perhaps the most well-known studies of altruism born of suffering concern the heroes of the Nazi era who sheltered or rescued Jews. This section reviews the work of Samuel and Pearl Oliner (1988, 2002) and Kristen Monroe (1996, 2002) as they investigated motivating forces behind the altruistic behaviors of rescuers of Jews in Nazi Europe. Samuel Oliner, founder and general director of the Altruistic Personality and Prosocial Behavior Institute, and Pearl Oliner, co-authored *The Altruistic Personality: Rescuers of Jews in Nazi Europe* in 1988. They characterize altruistic behavior as: 1) directed toward helping another, 2) involving a high risk or sacrifice to the actor, 3) accompanied by no external reward, and 4) voluntary. They further regard altruism as a continuum, with heroic altruism (involving greater risk to the helper) at one end, and conventional altruism (not normally life threatening to the helper) at the other end.

The Oliners extensively studied altruists including: 1) heroic Gentile rescuers of the Jews during the Holocaust), comparing them with 2) nonrescuers; and 3) hospice volunteers, or conventional altruists, comparing them with 4) non-hospice volunteers and non-volunteers in general. Over a period of several years, they conducted in-depth, taped interviews with more than 700 heroic rescuers, identified by the Holocaust Martyrs and Heroes Remembrance Authority. They analyzed interview data from those interview along with data from interviews they conducted with 93 conventional altruists (hospice volunteers) and 73 non-volunteers in order to characterize the range of motivations in helping. They found three categories of helping motivations across all four groups: 1) normocentric - those who had internalized the expectations of social groups, their moral community, or leadership of a highly regarded authority; 2) empathic - those who

responded from an aroused sense of empathy; and 3) autonomous/ principled - those who responded to their own overarching moral principles and were moved to action by what they considered violations of social justice and human rights principles.

Approximately 52% of the rescuer respondents' motivations fell into the normocentric category. These people mentioned feelings of obligation or duty coupled with anticipation of guilt or shame should they fail to act. Inaction, they claimed, would violate their community's norms of moral behavior. Thirty-eight percent of rescuers said they were moved empathically to engage in their first helping act. Their responses indicated that empathic reactions create overpowering feelings, usually expressed in distress, compassion, sympathy, and pity that lead people to react spontaneously. The direct face-to-face encounter with a person in need further heightens the impulse to act. Finally, 11% of rescuers were principle-motivated. These people described principles that were primarily religiously based.

The Oliners found that across the four groups, respondents' motivations often included an intermixing of the three helping motivations. A vast majority of the respondents (87%) cited at least one ethical or humanitarian reason for their actions. The ethical reasons cited included justice, fairness, and most importantly, the ethic of care and compassion (2002, p. 125).

The ethic of care from rescuers was typically expressed as: "I sensed I had in front of me human beings who were hunted down like wild animals. This aroused in me a feeling of brotherhood with the desire to help" (2002, p.125). Most rescuers assumed personal responsibility to relieve pain and suffering. While some rescuers felt affection

towards Jews who they knew personally, most (76%) expressed that they felt affection, compassion and concern towards Jews and others, in general. Rescuers were often (though not always) motivated by religious beliefs. One rescuer described his spirituality as all-encompassing: "I was always filled with love for everyone, for every creature, for things. I infuse life into every object. For me, everything is alive" (2002, p. 125).

Many rescuers noted having acquired their values of caring and social responsibility from their parents, their "models of moral and spiritual values" (2002, p.125). The values rescuers learned from their parents differed significantly from those learned by nonrescuers. Rescuers described learning an ethic and obligation *to all people.* Sorokin's term "extensivity" describes this caring orientation towards all people. Rescuers described this extensivity with the following: "They taught me to respect all human beings."; "I have learned from my parents' generosity to be open, to help people."; "I learned to be responsible, caring, and considerate."; and "He taught me to love my neighbor- to consider him my equal whatever his nationality or religion" (2002, p.125). Nonrescuers, in contrast, were often unaffected by suffering, more detached, and less receptive to others' helplessness and pain. Another interesting difference between rescuers and nonrescuers was the mode of discipline they received as children. Rescuers were more likely to have been disciplined by reasoning and explanation of the consequences of their misbehavior rather than by verbal or physical punishment, as was common among nonrescuers.

Oliner and Oliner (1988) concluded there is no single motivating explanation for altruistic behavior, rather a variety of factors converge. They found Gentile rescuers

risked their lives to act altruistically because they had learned care, compassion and social responsibility from their parents' values. In the developmental literature, positive socialization experiences have been identified as a key factor in the development of altruism and prosocial behavior (Staub, 2004, 2005), including a positive parenting style, responsiveness, empathic caretaking, and secure attachment (Eisenberg, 1992; Mikulincer et al., 2005; Staub, 2004). Caring and compassionate parents and other prosocial role models of morality and spirituality such as peers, teachers, and community leaders have been shown to predict prosocial behavior in all stages of development, including adulthood (Grusec, 1991; Mussen & Eisenberg, 2001; Piliavin & Callero, 1991). Furthermore, increased extensivity, or social responsibility, is correlated with higher acceptance of diverse groups and increased awareness of the connectedness with all living things. The Oliners (2002) stressed that altruistic actions "are usually the deeds of ordinary people whose moral courage arises out of the routine of their daily lives..." (p.136). The rescuers' caring compelled their action. They assumed responsibility not because others required it of them, but because failure to act would destroy others, and therefore, their shared sense of humanity.

Altruism as a perspective of shared humanity.

Kristen Monroe, director of the Program in Political Psychology at the University of California-Irvine, conceptualizes altruism as behavior intended to improve another's well-being even when there are risks to the altruist's safety or welfare (1994, 1995, 1996, 2002). Additionally, she posits altruism is best conceptualized along a continuum from pure self-interest to pure altruism, rather than dichotomies that miss much of the subtlety

of the phenomenon. Monroe conducted in-depth, narrative telephone or in-person interviews with philanthropists (n = 5), recipients of the Carnegie Hero Commission Award (n = 5), and rescuers of Jews in Nazi Europe during World War II (n = 13), each of whom met the conditions she postulated for altruism. Monroe also interviewed a "control group" of five entrepreneurs who were identified through personal connections and matched with philanthropists on age, gender, religion, etc. She examined three main questions: 1) Are there systematic sociocultural predictors of altruism? 2) Are there "corresponding systematic similarities in cognitive schema among altruists with respect to their self-perception and identity?" (1994, p. 5), and 3) How can we explain differences between altruists and the self-interested rational actors of economics? The interviews ranged from two hours to 20 hours and were taped and transcribed. A team of 3-6 analysts met and discussed themes that emerged from the transcripts.

Monroe (1996) found that cultural influences shaped the altruists' sense of the world and their relations to others. Specifically, she labeled the unique motivation of altruists to be their sense of "shared humanity" (p. 417). Monroe found "altruists look much like other human beings" (p. 420) in that none of the traditional sociocultural characteristics (age, gender, education, religion, socio-economic status, early childhood experience) predicted altruistic behavior. Rescuers and heroes came from both prominent and from humble family backgrounds, finished middle school and had PhDs, had no siblings and had many siblings, and were almost equally men and women (there were more women rescuers because more men were fighting in WWII). Though religion is often pointed to as a critical predictor of altruism, Monroe found it did not offer the

expected association; she shared this quote from a rescuer: "My feeling when doing it was that it had nothing to do with religion. If I were not a Christian, I would still do it. You have it in you" (1996, p. 417). Monroe concluded that what seemed more important than organized religion was a spiritual belief of closeness to others or of being part of a family. A rescuer shared: "When [people told Christ] 'You're the son of God,' he'd tell them, 'We are all sons of God.' And… if you think of God as creation, then we are all part of creation. We cannot today exist as individuals… There is no way to survive in this world unless we see ourselves as part of a whole" (1996, p. 419).

Furthermore, Monroe concluded that explanations for the behaviors of altruists based on self-interest, reciprocity, social learning, birth order, or kin selection produced only limited explanations for altruism. Familiarity and empathy, however, both explained the philanthropists' actions, but neither explained acts by rescuers or heroes. One factor that did appear more frequently and seemed more strongly related to altruism was a "common perception of themselves as individuals strongly linked to others through a shared humanity" (Monroe, 1996, p.417). Monroe concluded this perception of self as part of a common humanity- as opposed to personalistic ties to family or local interests or even gender or ethnic grouping—most aptly captured systematic and consistent differences in cognitive frameworks between altruists and the control group interviewees.

Particularly noteworthy, altruists perceived themselves as one with all humankind. This perception was such an intrinsic part of their cognitive orientation and self-definition, that it reflected two additional differences from the control group. Altruists engaged in more spontaneous behavior and felt they had a lack of choice in

executing the altruistic behavior (2002). One rescuer shared that "the hand of compassion was faster than the calculus of reason" (1996, p. 423), demonstrating how rescuers did not weigh the pros and cons of risking their lives to help the Jews; the majority simply responded spontaneously because, as one rescuer said, "What else could I do?" (1996, p. 422). Altruism seems to be an instinctive response that guided altruists' actions in saving others: "It's pretty near impossible not to help. You help people because you are human and you see that there is a need… There are things in this life you have to do, and you do it" (1996, p. 428). This lack of cost-benefit analysis, or any conscious calculus, about possible options was increasingly evident as individuals moved toward pure altruism (as judged by the consistency of their altruistic actions over the course of their lifetimes, as well as by the extent to which their altruism threatened their own lives and the lives of their loved ones). Their perceptions of themselves as part of all humanity constituted such a central core of their identity, it left them no choice in their behavior toward others.

Methodologically, Monroe's work deals with small samples of humans in non-experimental settings, thus limiting the generalizability of findings. Inclusion of a control group of five entrepreneurs offers an important contrast between non-altruists and altruists, however. Another strength of Monroe's studies (1994, 1995, 1996) is they reveal a new dimension to existing theories of moral action: the rescuers claimed they had *no choice* in their altruism. Instead of being guided by religion or reason, as previously suggested, Monroe found altruists acted from a sense of self, and a lived-out perspective of shared humanity. Her findings paved the way for a paradigm shift that

broadens conceptualization of the self by moving away from self-interest as the central aspect of human nature to assert that altruism does exist.

Altruism as attachment security.

Mario Mikulincer and Phillip Shaver (2001, 2003, 2005) have conducted extensive collaborative research on the topic of attachment. In 2005 they published a report of five experiments, replicated in two countries (Israel and the U.S.) investigating whether increases in attachment security foster altruistic behavior. They based their studies on Bowlby's (1969/1982) attachment theory, and had previously demonstrated how attachment security facilitates cognitive openness and empathy, strengthens self-transcendent values and fosters tolerance of out-group members (Mikulincer et al., 2001). Their results are consistent across experiments, allowing the researchers to rule out alternative explanations. They found that attachment insecurity (anxious attachment and avoidant attachment) suppressed or interfered with altruistic behavior whereas attachment security provided the foundation for empathy and altruistic behaviors toward others.

In the first study, Mikulincer and Shaver (2005) assessed participants' attachment styles, and then used a laboratory setting to assess their emotional reactions towards and willingness to help to a woman in distress. Participants were randomly assigned to one of three conditions relating to attachment security. The first condition subliminally primed participants with the names of secure attachment figures they had previously nominated. The two control conditions related to insecure attachment styles. The participants in the second condition were subliminally primed with names of close relationship partners who did not serve a secure-base function (anxious attachment); and participants in the third

condition were subliminally primed with names of acquaintances who were not close and did not serve as secure-base functions for the participant (avoidant attachment).

Participants were 90 American undergraduate students and 90 Israeli undergraduate students with equal numbers of men (n = 22) and women (n = 68) from each setting. All participants completed the Experience in Close Relationships Scale (ECR; Brennan et al., 1998), which assesses an individual's feelings in close relationships (Scale: 1 = *not at all,* to 7 = *very much*). Eighteen items correlate with attachment anxiety (e.g., "I worry about being abandoned") and 18 items correlate with attachment avoidance (e.g., "I prefer not to show a partner how I feel deep down"). Reliability and validity of the ECR have been demonstrated repeatedly (e.g., Brennan et al., 1998; Mikulincer & Florian, 2000).

Participants also completed a laboratory segment in which they watched another participant (a young woman confederate), through a video screen, while she performed a series of aversive tasks in a nearby room. The confederate became increasingly distressed by the tasks, and finally became very upset about having to pet a large, live tarantula in an open-topped glass tank. After a short break in the laboratory segment, participants rated their emotional reactions to watching this woman by completing a 24-item questionnaire assessing level of compassion and distress. Next, participants rated the extent to which they were willing to replace the confederate and perform the tasks she was expected to perform (Scale: 1 = *not at all*, to 7 = *very much*). After participants decided whether to trade roles with the confederate, they were fully debriefed and the experiment ended.

Overall, the results of the studies in both the U.S. and Israel provided strong support that thinking about a secure attachment figure was significantly more likely to activate compassion and helping behavior in response to another person's distress. Feeling personal distress at seeing another's distress was consistently associated with attachment anxiety and avoidance, whereas compassion and helping behavior were not.

In general this study, and the remaining four studies reported in this publication, seek to understand the effects of the attachment system on the caregiving system, two systems postulated by Bowlby (1969/1982). The "caregiving system" describes an innate behavioral system that responds to the needs of others who are either chronically dependent or temporarily in need. This behavioral system is thought to have evolved to complement the "attachment system," which governs people's, especially children's, emotional attachments to their caregivers. Mikulincer, Shaver and their colleagues demonstrated how the functioning of both systems is influenced by a person's sense of attachment security.

Extending their conceptualization and results to the broader realm of altruism, one can view the caregiving system as being activated by the presence of a distressed person, even a stranger in need, and its aim is to alter the needy person's condition until signs of increased safety, well-being, and security are evident. This innate, altruistic tendency to attend empathically to others' distress and provide care, however, can be suppressed, interfered with, or overridden by attachment insecurity. Under threat, people will often think first of turning to others to obtain support and comfort rather than providing support to others. At these times they are likely to be so focused on their own needs that they lack

the necessary capacity to attend to others' distress and engage in altruistic behavior. Based on their findings, the researchers hypothesized that only a relatively "securely attached person can perceive others not only as sources of support, but also as suffering human beings who have important needs and deserve support" (2005, p. 818). With this understanding, they concluded that "attachment security provides a solid and stable psychological foundation" (p. 831) to Batson's theory (1981) that empathy is activated into altruistic behavior.

Although gender was not found to play a significant moderating role in Mikulincer and Shaver's (2005) studies, the overrepresentation of women participation could be a limitation. Their research should be replicated with an equal sampling of men and women; additionally, future studies should include a male confederate (the distressed person) in order to more thoroughly examine the effects of gender on motivation to help. Furthermore, while attachment security was shown to have a significant effect cross-culturally between the Israeli and U.S. samples, future studies should investigate various sociocultural factors involved in motivation to help. Finally replication of these findings in a naturalistic setting would help to establish their external validity.

Strengths of these studies include Mikulincer and Shaver's breadth and depth of research in the area of attachment theory. Their findings highlight how attachment theory is a useful framework for both altruistic helping, as well as egoistic motives for helping or not helping. For instance, the researchers postulated that for people who are attachment avoidant and tend to defend their self-esteem (2003), helping others might be motivated by an egoistic desire to feel better about themselves.

Secure attachment appears to also be related to feelings of self-efficacy (confidence) when coping with distress (Mikulincer & Shaver, 2003). Feeling a sense of self-efficacy with respect to aiding those who suffer increases the likelihood of altruistic behavior, presumably because the individual believes their personal resources match the demands of the situation (Hoffman, 1981). In one study, adolescents' reports of empathic self-efficacy (e.g., "I can experience how a person in trouble feels") were positively related to their reports of sharing, helping, and taking care of others (Bandura et al., 2003). Considered together, these studies suggest an individual's secure attachment and feelings of self-efficacy are positively related to compassion/empathy and altruistic behavior and negatively related to distress (Bandura et al., 2003; Hoffman, 1981; Mikulincer & Shaver, 2003; Mikulincer et al., 2001, 2005).

Altruism as pathology.

Altruistic behavior is typically described in positive terms such as "giving" and "selfless" and valued as "commendable" and "beneficial." Yet, the point where altruism crosses a line and becomes its own "dark side" is neither widely acknowledged nor understood. "Pathological altruism" is a relatively new term, only entering the scientific literature three decades ago (McWilliams, 1984). Oakley (2011) discusses how altruism and empathy can be distorted and even pathological in her book, *Pathological Altruism* (2011). Oakley defines pathological altruism as "altruism in which attempts to promote the welfare of others instead result in unanticipated harm" (p. 3). A crucial qualification is that while the altruistic actor fails to anticipate the harm, "an external observer would conclude [that it] was reasonably foreseeable" (p. 4). Thus, she explains, if you offer to

help a friend move, then accidentally break an expensive item, your altruism probably isn't pathological; whereas if your brother is addicted to painkillers and you help him obtain them, it is" (p. 9).

Beginning with pathologies of empathy, Oakley describes how anxiety and depression may develop, as well as the burnout seen in many healthcare professionals. Oakley describes how pathologies of altruism can exist when promoting the welfare of others results in harm to others, such as codependency, social campaigners neglecting one's family, heroes risking leaving their children orphaned by saving strangers' lives, and champions of freedom and justice willing to kill (themselves or others) for their cause. Many people who engage in suicide attacks (suicide bombing, kamikaze, etc.) appear to be motivated to kill and die "for the best interests of others" (Williams et al., 2007; Yip et al., 2009). The more extreme the altruism, the more extreme the risks and costs altruists will likely accept in promoting the welfare of those whom they care about the most.

In recent history, the medical community has questioned whether living nondirected organ donors are pathologically altruistic (Henderson et al., 2003). In the first published investigation of the "altruism" of living unrelated kidney donors, Sadler et al. (1971) studied 18 unrelated living donors (9 of whom were nondirected donors) and found no evidence of psychopathology, psychological complications, or regret following donation. The researchers noted, however, that the medical community perceived that "no matter what, these people [living unrelated donors] must be abnormal to do such a thing" (p. 98). Skepticism among members of the medical community derives from their belief

that because donating a kidney provides no physical benefits for a living donor, those who wish to undergo this procedure without knowing their recipient must be psychologically unstable and therefore unable to give truly informed consent. Sadler et al. (1971) concluded, however, that there is no psychological reason to believe the desire to donate an organ to a stranger is a pathological obsession (p.99). Nonetheless, 30 years later, Spital (2001) found the assumption of pathological altruism persisted, as American transplant centers were "still reluctant to accept kidneys" from unrelated individuals (p.1063).

Ethical arguments abound regarding the nondirected donor issue. One argument is that since the offer to donate is being made altruistically, there is a greater likelihood that: a) the act is voluntary and autonomous, without the external pressure or emotional coercion of an ailing family member or loved one, and b) the donor is competent and fully informed and therefore able to give valid informed consent. Ethical considerations are discussed further in the "Factors influencing the decision to donate" section of this paper.

Scrutiny and skepticism from the American medical community toward those wishing to donate their organ appears to stem from fear of potential donors' pathological altruism. Henderson et al. (2003), a research group comprised of medical doctors, ethicists and psychologists, recognizing the dearth of information regarding the psychosocial profiles of nondirected donors, conducted a comprehensive analysis of 43 prospective nondirected donors. They assessed psychological stability, suitability, commitment and motivations for donations through the Comprehensive Psycho-Social

Interview (CPSI), Personality Assessment Inventory (PAI; Morey, 1991), and the revised NEO Personality Inventory (NEO PI-R; Costa & McCrae, 1992). The CPSI, developed for their study, is a 1.5-2 hour semi-structured interview exploring the participant's interpersonal relationships, perceptions of self and others, belief systems, values, life stresses, and thoughts and feelings about living organ donation. The PAI, a 344-item, self-report of adult personality, identifies psychopathological conditions relevant for clinical diagnosis. The NEO PI-R, a 240-item self-report inventory, measures the "Big Five" personality traits reflecting emotional, interpersonal, experiential, attitudinal, and motivational styles. The research team content analyzed interview responses to extract common motivational themes, and trained coders scored the PAI and NEO PI-R.

Results from the inventories revealed that 21 of the 43 participants (49%) met the criteria for psychological stability, suitability, and commitment to donation to be classified as potential-nondirected donors. Results of the content analysis of the interviews yielded 20 motivational themes. The most common motivations for potential nondirected donors were spirituality/ religion (57%), to substantially improve the quality of another's life (48%), and having had previous personal experience with transplantation or medicine (35%). Conversely, the most common motivations for those classified as non-potential nondirected donors were to increase their own self-esteem (27%), and to make a statement against their families (23%).

Thus, Henderson et al. (2003) found, contrary to the medical community's fears, a significant number of psychologically stable, altruistically-motivated individuals who wished to donate a kidney anonymously to a stranger, without seeking material

compensation. In fact, 49% of their sample met rigorous criteria to be considered an appropriate donor. These findings challenge the notion that psychological wellbeing is irreconcilable with altruism. The failure of 51% of the sample to meet the criteria, however, demonstrates the importance of evaluating potential donors' motivations and general psychological functioning. Given these results, it is unsurprising that healthcare professionals exercise extreme caution in this regard.

Altruism born of abundance.

On the opposite end of the psychological spectrum is a concept "altruism born of abundance" that Katrina Bramstedt, a medical ethicist, and Rena Down, a writer and recipient of a kidney from a stranger, portray in their book *The Organ Donor Experience: Good Samaritans and the Meaning of Altruism* (2011). Bramstedt and Down define "Good Samaritan donation" as living organ donation to an unknown individual—not a friend, relative, business partner, colleague, or associate. Their focus is on what moves an individual to undergo a personally unnecessary surgical procedure, discomfort and disruption of their lives to help an unknown person. They interviewed 22 living organ donors who had offered their organs (kidney, liver lobe or lung lobe) to complete strangers regarding their altruistic motivations.

They selected donors from 15 hospitals. In addition to participating in an interview, each donor completed a number of written measures, including the Volunteer Motivation Inventory (Esmond & Dunlop, 2004). The survey consists of 44 standardized statements of motivations for volunteering (Scale: 1=disagree and 5= agree). The statements were qualitatively coded and scored for ten different motivational categories,

including values, recognition, reciprocity, self-esteem, reactivity, social, understanding, social interaction, career development, and protective. The most highly scored category reflects the motivation of greatest importance to the donor, whereas the category with the lowest score reflects the motivation of least importance.

For 15 of the 21 donors, Values (helping others just for the sake of helping) was the top-ranking score. Three of these 15 individuals had tie scores with Values and either Reciprocity or Understanding. These motivational categories were consistent with the donors' interview responses. For instance, when asked directly, "What was your primary motivator?" the most common theme was "wanting to help," followed by "empathy."

Following Sorokin's (1950) query about neighborliness and Batson's (1991) connection of altruism with empathy, Bramstedt and Down (2011) also explored these concepts with donors by asking them two true-or-false questions: 1) *All humans belong to one family*, and 2) *As a child I sought out ways to correct injustice.* All but one donor expressed that all humans belong to one family and thus are "our neighbors." "Correcting injustice as a child" was interpreted as a form of reaching out to neighbors and was endorsed by thirteen donors.

Further attempting to explore the concept of empathy, the donors completed a written survey, the Interpersonal Reactivity Index (IRI; Davis, 1980), a validated and widely used measure in empathy research. The IRI consists of 28 situational items (Scale: 1 = Doesn't describe me well, and 5 = Describes me very well). The items assess four dimensions of empathy: two cognitive dimensions of *perspective taking* and *fantasy*, and two emotional dimensions of *empathic concern*, and *personal distress*. Each dimension

is analyzed and results in a final score ranging from 0-28. The highest scored dimension among donors was for empathic concern, followed by perspective taking, fantasy, and personal distress. There were no significant gender differences except for the category of personal distress. Female donor scores for personal distress were significantly higher than those of male donors.

A self-report measure was used to assess trust, along with one true-or-false question: *In general, the world is good.* Twenty donors self-reported they considered themselves to be "generally trusting of others," and 18 donors expressed a belief that the world, in general, is good, even though people behave badly at times. Sixteen of the donors reported having religious or spiritual beliefs, professing either a Protestant or Catholic affiliation. Thus, donors seemed to be trusting, had faith in the "basic decency of humanity," were positive and optimistic, and affiliated with religious or spiritual beliefs.

While there was no common demographic or socio-economic profile for the people who chose to donate, the qualitative interviews with the 22 Good Samaritan donors reveal two prominent themes: serving others and giving back to society. Bramstedt and Down hypothesized that witnessing and experiencing a helping-oriented profession leads to prosocial and altruistic behavior, as the developmental literature suggests (Staub, 2004, 2005). Serving others was seen occupationally, as 16 donors were in service-oriented jobs at the time of their donation. Four of the donors identified an adult in their upbringing who contributed to their volunteerism; eight donors were involved in volunteer activities (including military, Rotary, hospitals and nursing homes,

Boy Scouts and Girl Scouts, and pastoral care) prior to/after organ donation. Almost all of them had previously donated blood or marrow.

The theme of *giving back to society* was prevalent in 13 of the interviews. Their motivation to give back resembles what Bramstedt and Down called "altruism born of abundance." They defined "altruism born of abundance" as acts that are realized by individuals who have reached a stage of contentment in their lives. Abundance, in this sense, refers to a state of personal contentment and satisfaction that does not necessarily correlate with material or financial wealth. These people arrange their many segments of life (including education, career, mental and physical health, family, friends, finances, spirituality, and identity) to find a combination that creates their unique picture of life satisfaction. Most of the donors were not wealthy (average household income was $51,000 to $75,000 during the year in which they donated). They also did not have high-powered jobs. The authors concluded they are people with a lot of empathy who used language to describe themselves as "blessed," "lucky," "fortunate," or desiring to "give back." In fact, most of the donors viewed their second kidney as "more than what they needed." These donor characteristics suggest individuals who are keenly aware of their contentment and abundance and look outward to find ways to distribute their blessings to others.

Strengths of this study include Bramstedt's formal training as a transplant ethicist, academic professor and journal editor to use language that speaks across disciplines (e.g., "altruism born of abundance"). The book is written in everyday language that addresses pivotal questions such as: Are we prewired to be altruistic or do we learn altruism?

Another strength is the data were obtained using both qualitative and quantitative measures. A limitation is that the donors were all from a Western culture and some measures, including the Volunteer Motivation Inventory, were developed in and based on volunteers in Western culture. Finally, qualitative data are not intended to be generalized to the population of interest.

What Factors Affect the Donation Decision-Making Process?

What differentiates those who donate from those who do not? How do kidney donors make the decision to donate? Do donors feel capable of making an informed decision at the time of their decision to donate? More specifically, are they fully informed and is their decision is voluntary? Recent psychological and medical research attempts to answer these ethical questions.

Competence and informed consent

Part of the hesitation among members of the American medical community in embracing living organ donors stems from the lack of any clear benefit to the donor while there is some physical and perhaps psychological risk. Their hesitation is even stronger in the case of a nondirected donor. As mentioned earlier, psychopathology is presumed because living nondirected donors not only reap no clear benefit, they do not know the recipient. Ethical considerations in living kidney donation include donors' competence, capacity to give free (non-coerced) and informed consent, and the voluntary nature of their organ donation. Over 40 years ago, Fellner and Marshall (1970) interviewed 20 kidney donors and found most decided to donate "immediately," and "not one of the donors weighed alternatives and rationally decided" (1970, p.1249). These findings led

the researchers to question the competence (or lack thereof) involved in the donors' decision- making process. A more recent study of 98 living kidney donors yielded similar results: More than 75% of donors decided almost immediately, and disclosure of relevant information made little difference to their decision (Stothers et al., 2005).

Landolt et al. (2001) took a deeper look into questions of competence and informed consent. They surveyed 500 British Columbia residents by phone about whether they would contemplate living kidney donation to particular individuals (child, parent, relative, spouse, friend, and stranger). The researchers explored the impact of increased knowledge about living donation on the participant's willingness to donate. The informed condition, which included a 1-minute information preamble outlining the operation, and potential benefits and risks to donors and recipients, was added to ensure that participants had a realistic sense of what it meant to be a donor.

Twenty-nine percent of participants said they would contemplate donation to a stranger. The researchers noted several differences between those willing to contemplate such donation and those who were unwilling. Specifically, potential donors were significantly more likely "to report trusting the safety of transplant procedures, wanting to help others by donating their organs after death, believing that their organs could be used to help somebody live a healthy life, and having thought more about organ donation in general" (2001, p.1694). There were no significant differences in willingness to donate between the uninformed and informed conditions. The researchers speculated that the information might not have been internalized or used in participants' decision-making

process. Landolt et al. proposed the decision to donate a kidney (whether hypothetical or real) may not be an entirely rational decision-making process.

Evidence suggests this is true in the case of both living related and unrelated donors (Roff, 2007; Simmons et al., 1987; Toronyi et al., 1998). Indeed, much research shows many medical decisions are made on the basis of feeling rather than careful weighing of alternatives. For example, Kass and colleagues (1996) found willingness to participate in medical experimentation was based to a greater extent on trust in care providers than on weighing the information in the consent form. Perhaps decisions about an emotion-laden subject such as organ donation are processed more by the "heart" and less by the "head" (Landolt et al., 2001), which raises questions about the extent to which decisions made by the heart are competent ones.

Finally, Landolt et al. (2001) found demographic differences among participants who were willing to donate to someone genetically/emotionally related (directed) versus those willing to donate to a stranger (nondirected), and those unwilling to donate to anyone (nondonors). Nondonors were more likely to be older (50% over age 65), single, and have lower incomes (68% under $35,000/yr) than either directed or nondirected donors. A transplant operation, with a 6–8-week rehabilitation and subsequent time off work, requires a person to be of optimal physical health, have some financial stability, and a strong social support network; these resources may not have been available to the self-reported nondonors.

In contrast, nondirected donors tended to be middle-aged: old enough that Landolt and colleagues supposed "childcare responsibilities are likely diminishing, giving the

potential donor more flexibility to bear the consequences of this decision, and still young enough that health issues might be less of a concern than for the older individuals that predominated the nondonor group" (2001, p.1694). Nondirected donors were also more likely to be living in a family group than nondonors. The authors concluded family composition was a key factor in determining whether an individual would consider being a nondirected donor; they recommended future investigations about the role of social support for organ donors, both within and outside the family, in the decision-making process.

Voluntariness and autonomy.

Ethical concerns regarding competence and informed consent arise regardless of the type of organ donation (i.e., nondirected versus genetically or emotionally-related organ donation). When someone donates their organ to a loved one, is it their free choice? Were they emotionally coerced? Does their decision stem from guilt? Are they seeking to be securely attached to another via their donation? While living related organ donors may be fully competent, their decision making capacity may be compromised by their attachment security, social pressure, the cultural context, and/or other circumstances. Much literature expounds on the ethical responsibilities of transplant doctors and the psychologists who evaluate donors concerning competence, informed consent and autonomy (e.g. Landolt et al., 2001; Spital, 2001; Roff, 2007). Such evaluations are designed to understand the donors' perspective and the validity of their perspective on their perceived competence, consent and voluntariness in giving their organ to another person.

Living organ donation is a complex ethical, moral, medical and psychological issue. Ensuring the voluntary nature of such an emotion-laden decision is difficult; ensuring a detailed understanding of the potential psychological harms and benefits is even more difficult. In the case of related donation, evaluation of these aspects of informed consent appear to be somewhat more resolved, perhaps justified by the psychological and emotional benefits that arise from witnessing the improved health of the recipient (Toronyi et al., 1998). In unrelated and nondirected donation, however, understanding both the psychological benefits and harms to the donor are more nebulous.

Psychological Effects of Organ Donation

What happens psychologically after healthy donors have an invasive physical surgery and alteration to their body? In the case of unrelated and nondirected donation, this conclusion is neither obvious nor straightforward.

Benefit and harm, post-donation.

Clemens et al. (2006) and Dew et al. (2012) systematically reviewed all studies between 1969 and 2006, and 1986 and 2012, respectively, that used a survey-based approach to understand donor psychosocial health after donation. They concluded that the literature converges in suggesting although many individuals experience no adverse psychosocial consequences of donation, others develop enduring somatic complaints (e.g., fatigue, pain), psychological distress (e.g., depressive or anxiety symptoms) and/or strained relationships with family members (Olbrisch et al., 2001; Schroder et al., 2008; Schover et al., 1997; Simmons et al., 1987). Some findings suggest over half of all donors may experience such difficulties (Schroder et al., 2008).

In particular, there is evidence that those donors who experience poor psychological outcome post-donation share a common characteristic of ambivalence regarding the prospect of donation (e.g., lingering feelings of hesitation and uncertainty about their intention to donate). Thus, ambivalence pre-donation appears to be a critical predictor of poor psychosocial outcome post-donation (Dew et al., 2012; Schover et al., 1997; Simmons et al., 1987). Feelings of lingering hesitation and uncertainty were common, found consistently in about 75% percent of prospective donors. (Dew et al., 2012).

Do organ donors receive unintended psychological benefits from their donation? The literature vaguely alludes to boosts in self-worth and feelings of deep purpose, but there are no robust data concerning the psychological benefits, if any, the donors experience post-donation (Dew et al., 2012). Dew et al. concluded that about 95% of donors say they would do it again, suggesting there seems to be some positive personal "consequence," psychologically, from their actions.

Summary

Empirical evidence of altruistic motivation in humans provides scientific fuel to philosophical questions that have been circulating for centuries. Universal egoism—the assumption that all human behavior is motivated by self- interest—has long dominated not only psychology but biology, political science, economics, sociology, and medicine, among other fields. This view is challenged by a more complex perspective that allows for altruism as well as egoism. Altruism implies that other people can be more to us than *just* sources of information, stimulation, gratification, and reward as we each seek our

own welfare. We have the potential to care about others for their sakes, not simply for our own. Prior researchers have used a variety of tools to understand altruism and what motivates living organ donors. Consensus is lacking, however, about the briefest yet most valid way of screening the motivations and decision-making process of potential living kidney donors.

The present study consisted of a survey of a large sample of living kidney donors, including related donors and unrelated donors. There are three major research questions: (1) What is the prevalence of altruism among living kidney donors? (2) How do related and unrelated donors compare in their degree of altruism? and (3) From select measures used in prior research, which items are the strongest predictors of individuals who are high versus low in altruism?

Chapter 3: Methodology

Participants

Upon receipt of approval from a University of Minnesota Institutional Review Board (see Appendix A), participant recruitment processes commenced. First, an invitation was sent via by email on November 17, 2014 (see Appendix B) or by U.S. mail on November 6, 2014 (see Appendix C) to a representative random sample of 253 kidney donors from the University of Minnesota Kidney Donor Transplant Program list. The invitation requested their participation in a survey (see Appendix D). Inclusion criteria for study participation are: 1) previous adult donor (related or unrelated) through the University of Minnesota Kidney Donor Transplant Program; 2) known to be alive; 3) had previously consented to be contacted to participate in future research related to living donation, as ascertained from the OTTS database; 4) able to read, write and speak English; and 5) willing to provide informed consent for the present study. Exclusion criteria for study participation include: 1) any former University of Minnesota living kidney donor who has indicated they do not want to be contacted by research, as documented in the OTTS database; 2) any former University of Minnesota living kidney donor for whom there is no current contact information; and 3) vulnerable populations, including minors and prisoners. A flowchart for participant recruitment is shown in Figure 1.

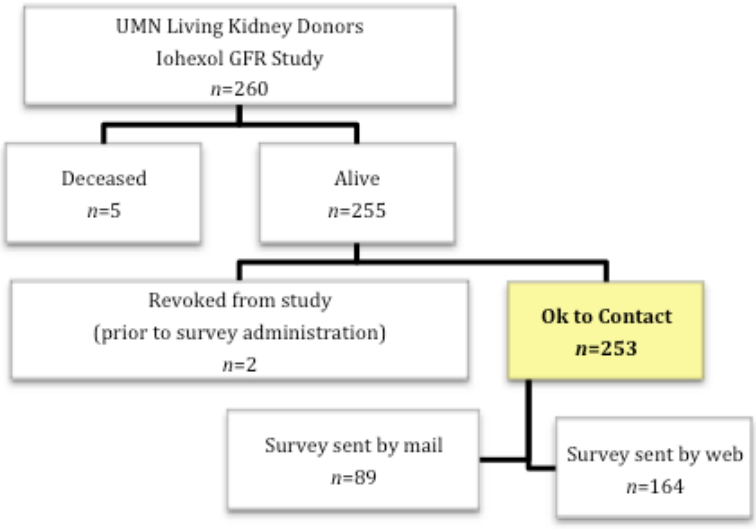

Figure 1. Participant Recruitment Flowchart

The invitation included a description of the study, informed consent, and a link to the survey, which was available through a secure OTTS database. Potential participants were told the purpose of the study is to understand the role of altruism in kidney donation.

Instrumentation

Survey.

This investigator created a survey (Appendix D) based on survey items measuring altruism used in extant studies and in consultation with an experienced medical doctor, two licensed psychologists, and a certified genetic counselor. The goal of the survey is to create a tool that could be used to measure a potential living kidney donor's altruism. To test for clarity of content, the survey was piloted on 3 members of the University of Minnesota Renal Disease and Hypertension Research team. Feedback from the pilot participants was used to help the investigator determine which variables to focus on,

which items to retain, delete or modify from the survey, and in which areas new items were needed. Feedback from the research team was not part of the data analyses for the present study.

The final version of the survey consists of 51 items from 3 separate surveys. "Survey 1" is the Helping Attitude Scale (HAS) developed by Nickell (1998) and published in *Positive psychology: The scientific and practical explorations of human strengths (2nd ed.)* (Snyder et al., 2011). The HAS contains 20 items that measure general beliefs related to helping others (e.g., "Volunteering to help someone is very rewarding"). Items are rated on a 5-point Likert scale where 1= "strongly disagree" and 5 = "strongly agree." The survey has been used in many published studies (e.g., Corwin, 2005; Dulin & Dominy, 2008, Lemmens et al., 2009; Reizer & Mikulincer, 2007; Smith, 2009; Wijnaert & Bouwman, 2009; Wilhelm & Bekkers, 2010). Scores can range from 20-100, with higher scores associated with higher altruism.

"Survey 2," is the Self-Report Altruism Scale (SRAS; Rushton et al., 1981) and contains 20 items. The SRAS survey measures self-reported frequency with which a respondent has engaged in specific altruistic behaviors (e.g., I have donated goods to charity). Items are rated on a 5-point Likert scale, where 1 = "never" and 5 = "very often." Scores range from 20 to 100, with higher scores indicating greater altruism. The scale authors consider a score of 60 to be neutral (Ruston et al., 1981).

Both the HAS and the SRAS were validated on "normal" college students, with means of (79.6±8.7) and (55.6±11.0), respectively. Internal consistency reliability, using Cronbach's alpha were α= 0.86 and 0.84, respectively.

"Survey 3," is the Altruism and Gift Giving Battery (AGGB; Bhaskaran, 2008), an unpublished scale consisting of 11 items related to gift giving. This AGGB measures self-reported agreement that a respondent has engaged in gift-giving behaviors (e.g., I generally give gifts because people expect me to give them). The items are rated on a 5 point Likert scale, where 1 = "strongly disagree" and 5 = "strongly agree." The AGGB items were included on the present survey in order to gather initial reliability and validity data.

Following each of the three scales, two additional items ask respondents: 1) to report (Yes/No) if the scale items would be applicable in measuring the altruism of living kidney donors; and 2) which scale items in particular they believe are not relevant to living kidney donors. A final question asks respondents to think of and list any questions they regard as important in determining the altruism of kidney donors that were not covered by the three scales.

Procedures

The survey was delivered through email (see Appendix B) or mail (see Appendix C), in accordance with preferences stated by donors in the OTTS database (see Figure 1 for flowchart). A follow-up phone call (see Appendix E for script) was made approximately two weeks later to potential participants who had not yet returned the survey (n =105). The survey remained open until the end of December 2014. The data were entered and stored in the University of Minnesota Kidney Donor Transplant Program database.

Data Analysis

Data cleaning.

Before undertaking any detailed analysis, responses were vetted for consistency and completeness. If a survey was incomplete, the research team removed incomplete items from the analysis, but retained responses to completed items where possible. Surveys were partitioned into two subgroups for comparison based on type of donation: related and unrelated.

Descriptive statistics.

Ordinal scale data were coded into numerical scores. Means, medians, standard deviations, *n*'s, ranges, percentages, and correlations were calculated for survey items as appropriate.

Inferential statistics.

Zero order correlations were computed, as appropriate, for responses to survey items. Exploratory factor analysis was used for data reduction purposes, and to group survey items into related concepts. These factors were used in subsequent multiple variable analyses. Multivariable analyses were used initially to compare the three groups on major variables, followed by post-hoc comparisons of any statistically significant results.

Analysis of open-ended responses.

Content analysis is a widely used qualitative research technique for interpreting meaning from the content of text data (Krippendorff, 1989). The last survey item elicited open-ended responses, "What questions do you think are important to ask but were not covered by these surveys?" Each response was considered one unit of analysis and was

thematically coded into as many categories as applicable. Each category was then assigned a name reflecting its major theme. A licensed psychologist served as the data auditor, reviewing the groupings and selected quotations, with any disagreements being discussed to reach consensus.

Chapter 4: Results

This chapter begins with a description of the demographic characteristics of the living kidney donors who completed the survey. A description of data cleaning is provided with reports on how missing data were handled. Next, descriptive statistics are reported for respondents' degree of altruism, and then compared by group: living related donor (LRD), living unrelated donor (LURD), and normative sample. Finally, the results of a quantitative analysis of survey responses using factor analysis to group survey items into related concepts and multivariable analyses to compare the two donor groups (related and unrelated) on major variables are presented.

Participant Demographic Characteristics

Of the 253 potential participants from the representative random sample of living kidney donors from the University of Minnesota, seven individuals were unreachable because they are either deceased (n = 1) or their mailing was returned as undeliverable (n = 6). One hundred seventy-one of the remaining potential participants responded to the survey (a 69.5% response rate). Donors who completed the survey by web (n =112) were required to answer all numerical fields before submitting the survey. Donors who completed and returned a survey by U.S. mail (n =59) could leave items blank. There were a total of 56 missing items across 42 participants (mean = 1.33, Range = 1-4). Using the cutoff of 20% missing data established by Peng, Harwell, Liou, and Ehman (2006), three participants were removed from analyses, leaving a final sample of 168 participants. Demographic information for survey respondents and for those who did not respond or declined participation is presented in Table 1.

Table 1
Demographics for Survey Respondents and Non-Respondents at the Time of Donation

	Respondents (N= 168)				Non-Respondents (n = 85)			
Variable	*n*	%	Mean	*SD*	*n*	%	Mean	*SD*
Age								
At Donation			40.8	11.1			40.8	11.3
Sex								
Female	106	63%			49	58%		
Male	62	37%			36	42%		
Employment								
Yes	125	74%			71	84%		
No	11	7%			4	5%		
Unknown	32	19%			10	11%		
Education								
Grade (0-8)	1	1%			1	1%		
High School	32	19%			29	34%		
Technical College	36	21%			18	21%		
Undergraduate	36	21%			20	24%		
Graduate School	21	13%			5	6%		
Unknown	42	25%			12	14%		
Employment								
Full time	65	39%			30	35%		
Part time	13	8%			3	4%		
Other	15	9%			17	20%		
Unknown	75	45%			35	41%		
Marital Status								
Married	104	62%			55	65%		
Divorced	8	5%			6	7%		
Never Married	26	15%			21	35%		
Other	4	2%			0	0%		
Unknown	26	15%			3	3%		
Ethnicity								
Caucasian	161	95%			81	95%		
Black	3	2%			2	3%		
American Indian	2	1%			1	1%		
Hawaiian	1	1%			1	1%		
Hispanic	1	0%			0	0%		
Donor Status								
Living Related	132	79%			70	82%		
Living Unrelated	36	21%			15	18%		

Note. Unknown refers to donors who did not disclose that information.

As shown in Table 1, the mean age of survey respondents was 40.8 (*SD*=11.1). Most were female (*n*= 106, 63%), self-identified as Caucasian (*n*=161, 95%), were married (*n*= 104, 62%) and were related donors (*n*= 132, 79%). While most respondents were employed at the time of their donation (*n*= 125, 74%), some were employed full-time (*n*=65, 39%), whereas a smaller percentage was employed part-time (*n*=13, 8%). Additionally, respondents' highest level of education at the time of their donation was almost equally dispersed among high school (*n*=32, 19%), technical college (*n*=36, 21%), undergraduate school (*n*= 36, 21%) and graduate school (*n*= 21, 13%). Statistical analyses yielded no statistically significant differences in the demographic characteristics of respondents and non-respondents; therefore the sample appears to be representative of the population of living University of Minnesota Kidney Donors. Table 2 contains a summary of the demographic characteristics of the LRD and the LURD groups.

Research Question 1: What is the Prevalence of Altruism Among Living Kidney Donors?

Descriptive statistics were calculated to determine the mean altruism scores for the total sample of respondents and for each donor group. As shown in Table 3, on the first scale of the survey, the Helping Attitude Scale (HAS), the mean for the total sample was 86.9 (*SD*=7.6; Range = 61-100). This is a significantly higher mean than the reported normative data for the scale (*M*=79.6, *SD*= 8.7), $t(167) = 12.43$, $p < .001$.

For the second scale, the Self-Report Altruism Scale (SRAS), the mean score for the total sample was 63.6 (*SD*= 9.5; Range = 43-88). Respondents again scored

Table 2
Demographic Characteristics of Living Related Donor (LRD) and Living Unrelated Donor (LURD) Respondents

	LRD (n = 132, 79%)		LURD (n=36, 21%)		Total N = 168	
Variable	*n/M*	%/ *SD*	*n/M*	%/ *SD*	*n/M*	%/ *SD*
Age						
At Donation	38.8	10.9	48.3	8.3	40.8	11.1
Sex						
Female	87	66%	19	53%	106	63%
Male	45	34%	17	47%	62	37%
Employment						
Yes	100	76%	25	70%	125	74%
No	8	6%	3	8%	11	7%
Unknown	24	18%	8	22%	32	19%
Education						
Grade (0-8)	1	1%	0	0%	1	1%
High School	28	21%	4	11%	32	19%
Technical College	28	21%	8	22%	36	21%
Undergraduate	29	22%	7	20%	36	21%
Graduate School	13	10%	8	22%	21	13%
Unknown	33	25%	9	25%	42	25%
Employment						
Full time	45	34%	20	56%	65	39%
Part time	10	8%	3	7%	13	8%
Other	36	27%	11	31%	15	9%
Unknown	41	31%	2	6%	75	45%
Marital Status						
Married	81	61%	23	64%	104	62%
Divorced	6	5%	2	6%	8	5%
Never Married	22	17%	4	11%	26	15%
Other	3	2%	1	2%	4	2%
Unknown	20	15%	6	17%	26	15%
Ethnicity						
Caucasian	130	98%	36	100%	161	95%
Black	1	1%	0	0%	3	2%
American Indian	1	1%	0	0%	2	1%
Hawaiian	0	0%	0	0%	1	1%
Hispanic	0	0%	0	0%	1	1%

Note. Unknown data exists because donors chose not to share that information.

significantly higher than a normative sample from the general population (M=55.6, SD=11.0), $t(167) = 10.29$, $p < .001$.

For the final scale of the survey, the Altruism and Gift Giving Battery (AGGB), the total sample of respondents had a mean score of 39.2 (SD= 7.0; Range =22-55). There are no normative data available for this scale.

Research Question 2: How do Related and Unrelated Donors Compare in their Degree of Altruism?

Statistical analysis of scores for the LRD and LURD groups on the three scales showed no significant mean differences. Sensitivity analysis revealed an effect size of Cohen's f^2 = .07 (moderate effect size) would be detected with .80 power. The means and standard deviations for both groups are presented in Table 3.

Table 3
Means and Standard Deviations for Three Altruism Scales for the Total Sample, Each Donor Group, and a Normative Group

Scale	LRD n=132		LURD n= 36		Total Sample N=168		Normative	
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Survey 1(HAS)	86.5	7.4	88.5	8.7	87.5	8.1	79.6	8.7[a]
Survey 2 (SRAS)	62.9	10.4	66.1	8.2	64.5	9.3	55.6	11.0[b]
Survey 3 (AGGB)	39.4	7.1	38.5	6.6	38.9	6.9	N/A	N/A

Note. Source: [a] Nickell (1998); [b] Rushton et al. (1981); HAS = Helping Attitudes Scale; SRAS = Self-Report Altruism Scale; AGGB = Altruism and Gift Giving Battery

Research Question 3: Which Scale Items are the Strongest Predictors of Individuals Who are High versus Low in Altruism?

Reliability analyses were conducted on the three scales prior to factor analysis. All three scales showed high reliability: Scale 1 (HAS): α = .85; Scale 2 (SRAS): α = .86;

and Scale 3 (AGGB): $\alpha = .84$. A principal axis factor analysis using Promax rotation was conducted on the 51 scale items. The results of this analysis are shown in Table 4. The items "I have donated blood," "I generally give gifts because people expect me to give them," and "I almost never give gifts to people unless it is for a special occasion or holiday" did not load onto any factor and were discarded. Visual analysis of the scree plot yielded four factors that accounted for 34% of the variance in altruism scores.

Factor 1: Physical help to stranger. This factor includes 17 items that indicate the respondent offers a stranger concrete, physical aid. Examples of items loading on this factor include: "I have offered to help a handicapped or elderly stranger across the street," "I have made change for a stranger," and "I have given directions to a stranger."

Factor 2: Gifts. This factor includes nine items that describe care through gift giving tendencies. Examples of items loading on this factor include: "Carefully selecting and giving gifts is an important tradition for me," "I almost always try to give gifts that convey a very personal message to the receiver," and "I almost always exert considerable effort to select or make special gifts for close members of my family."

Factor 3: Volunteerism rewards. This factor includes 13 items pertaining to the emotional or psychological rewards of volunteerism. Examples of items loading on this factor include: "It feels wonderful to assist others in need," "Volunteering to help someone is very rewarding," and "I feel at peace with myself when I have helped others."

Factor 4: Risk/sacrifice in helping. This factor includes nine items that pertain to the potential risk or sacrifice to one's self involved in helping another person. Examples of items that load on this factor include: "If the person in front of me in the

check-out line at a store was a few cents short, I would pay the difference," and "If possible, I would return lost money to the rightful owner."

Table 4
Summary of Principal Axis Factor Analysis with Promax Rotation

(Scale #) Survey Items	Factor			
	1	2	3	4
(2) HELP_ELDERLY_STRANGER	.648			
(2) MAKE_CHANGE_STRANGER	.630			
(2) GIVE_DIR_STRANGER	.625			
(2) HELP_CARRY_BELONG	.594			
(2) LET_BORROW_ITEM	.588			
(2) OFFER_SEAT_STRANGER	.566			
(2) HELP_CLASSMATE	.552			
(2) GIVE_STRANGER_LIFT	.513			
(2) HELP_PUSH_CAR	.506			
(2) HELP_ACQUAINTANCE	.503			
(2) GIVE_MONEY_STRANGER	.502			
(2) ALLOW_AHEAD_LINEUP	.496			
(2) POINT_OUT_CLERK_ERROR	.478			
(2) DELAY_ELEVATOR	.450			
(2) HOLIDAY_CARD_CHARITY	.387			
(2) LOOK_AFTER_PET_CHILDREN	.357			
(2) DONATE_CLOTH_CHARITY	.260			
(3) SELECT_GIVE_GIFT		.860		
(3) ALWAYS_GIVE_GIFT		.855		
(3) MAKE_SPECIAL_GIFT		.793		
(3) ENJOY_GIVE_GIFT		.712		
(3) SHOW_FRIENDSHIP		.711		
(3) GIVE_ALOT_GIFT		.660		
(3) BUY_GIFT_RECEIVER_TASTE		.636		
(3) GIFT_LOVE_OTHERS		.623		
(3) BUY_MOST_GIFT		.386		
(1) GOOD_ASSIST_OTHER			.792	
(1) VOLUNTEER_HELP			.761	
(1) PEACE_MYSELF			.713	

(1) ENJOY_AID_OTHER	.696	
(1) TAUGHT_HELP_OTHER	.645	
(1) OFFER_HELP	.550	
(1) HELP_FRIEND_FAMILY	.490	
(1) DONATE_CHARITY	.440	
(1) DONATE_ORGAN	.411	
(1) CONTRIBUTE_MONEY	.324	
(2) GIVE_MONEY_CHARITY	.312	
(1) DISLIKE_GIVE_DIRECTIONS	.298	
(2) VOLUNTEER_WORK_CHARITY	.286	
(1) PAY_DIFFERENCE		.655
(1) RETURN_LOST_MONEY		.628
(1) AID_POOR		.613
(1) HARM_WHEN_HELP_PEOPLE		.564
(1) VOLUNTEER_MAKE_HAPPY		.535
(1) AVOID_AID_SOMEONE		.447
(1) FEEL_PROUD_TO_AID		.447
(1) NOT_HELP_ELDER		.401
(1) HELP_OTHER		.328

Note. Factor names: 1- *Physical Help to Stranger*; 2- *Gifts*; 3- *Volunteerism Rewards*; 4- *Risk/ Sacrifice in Helping*.

Next, a MANOVA was conducted to test for differences between LRD and LURD on any of the four factors. The MANOVA was not significant, Wilks's $\lambda = 0.934$, $F(4,129) = 2.269$, $p = .07$. Sensitivity analysis showed an effect size of Cohen's $f^2 = .09$ (moderate effect size) would be detected with .80 power.

Finally, exploratory model fitting using logistic regression was performed to try to predict the likelihood of being a living unrelated donor based on the four factors and demographic variables for the present sample ($n = 168$). In order to decide which demographic variables to include in the model, univariate tests were conducted to determine whether there were any demographic differences for the LRD and LURD groups. There was one statistically significant difference for age, $t(166) = -4.85$, $p < .001$,

such that those in the LURD group were older on average than those in the LRD group. Chi-squared tests found no significant group differences for gender (p = .15), education (p = .38), employment status (p = .74), employment description (p = .10), or relationship status (p = .95). Thus, only age was used as a covariate in the regression model.

The results of the logistic regression are summarized in Table 5. Significant predictors of LRD/ LURD included: Factor 3 (*OR*= 0.51 [0.28, 0.94]), Factor 4 (*OR*= 4.14 [1.61, 10.64]), and age (*OR*= 1.11 [1.05, 1.17]). For every year older a donor gets, s/he is ~11% *more* likely to be a living unrelated donor, with all else being equal. For every 1-point increase in Factor 4, the donor is about 4.14 times *more* likely to be a living unrelated donor, with all else being equal. For every 1-point increase in Factor 3, the donor is about 1.95 times *less* likely to be a living unrelated donor. Factors 1 and 2 were not significant.

Table 5
Results of Logistic Regression Modeling Prediction of Becoming a Living Unrelated Donor

Variable	R^2	B	SE	z	p	OR [95% CI]
Initial model[a]	.32					
Intercept		-5.924	1.270	21.770	.00	
Factor1		.123	.285	.185	.67	1.13 [0.65, 1.98]
Factor2		-.345	.258	1.782	.18	0.71 [0.43, 1.18]
Factor3		-.670	.309	4.691	.03	0.51 [0.28, 0.94]
Factor4		1.420	.482	8.668	.003	4.14 [1.61, 10.64]
Age		.104	.026	15.564	.00	1.11 [1.05, 1.17]

Note: [a]The reference category is living related donor; R^2 reported is Nagelkerke's R^2; Factor 1: Physical Help to Stranger; Factor 2: Gifts; Factor 3: Volunteerism Rewards; Factor 4- Risk/ Sacrifice in Helping.

Respondents' Perceptions of Whether the Scales Assess Altruism

The sample was asked to indicate whether they believed each scale assesses altruism. One hundred seventeen respondents (71%) indicated that the HAS would determine if a potential donor were altruistic. One hundred nineteen respondents (73%) reported that the SRAS would determine if a potential donor was altruistic. Only 63 respondents (41%) reported that the AGGB scale would determine if a potential donor was altruistic.

Qualitative Analysis of Comments about Relevant Survey Items

Survey 1: HAS. Sixty-one of the 168 participants (36%) responded to the open-ended question: "Which question(s) in Survey #1 do you feel are **not** relevant to living donation?" Three items were endorsed by at least 25% of the respondents to the question:

"I dislike giving directions to strangers who are lost."

"I donate time or money to charities every month."

"I rarely contribute money to a worthy cause."

Survey 2: SRAS Sixty-five of the 168 participants (39%) responded to the question "Which question(s) in Survey #2 do you feel are **not** relevant to living donation?" One item was endorsed by at least 25% of the respondents to the question:

"I have given a stranger a lift in my car."

Survey 3: AGGB. Seventy-four the 168 participants (44%) responded. One item was endorsed by at least 25% of the respondents to the question:

"I almost never give gifts to people unless it is for a special occasion or holiday."

Qualitative Analysis of Comments Regarding the Inclusion of Unasked Questions

Seventy- eight of 168 participants (46%) responded to the qualitative question: "What questions do you think are important to ask but were not covered by these surveys?" Content analysis of these responses yielded seven themes. Four of these themes contain suggestions of actual questions, while three themes contain general comments. Responses were multi-faceted and were coded into as many themes as applicable. Six responses were categorized as "Miscellaneous" because they could not otherwise be classified within themes; these responses either consisted of logistical feedback about the survey or personal reactions to the items contained in the survey. A complete list of comments, grouped by theme, is contained in Appendix F.

Theme 1. Questions regarding the donor's cultural ideas of giving (*n*=20). This theme pertains to questions that explore familial, religious or social norms around giving. Responses illustrating this theme include the following:

> "As you were raised, do you have a family history of volunteering and helping others?" *(LURD)*
>
> "Is giving a part of your religious belief?" *(LRD)*

Theme 2. Questions regarding how much risk and discomfort one is willing to endure for another (*n*= 17). This theme refers to responses suggesting questions about the importance of helping or saving another person's life at a great cost to one's own life. Responses illustrating this finding include:

> "Are you willing to risk your health to benefit another human being?" *(LURD)*
>
> "Would you accept pain so someone else would not have to feel pain?" *(LRD)*
>
> "Have you ever risked bodily harm to aid someone else?" *(LRD)*

> "I am willing to experience some personal short-term pain for a possible long-term success for another?" *(LRD)*

Theme 3. Comments regarding personal family obligation or selfish motivation (*n*= 14). This theme concerns comments related to the participants' personal experiences of being a donor and acknowledging that their intentions were not altruistic, that they were either motivated selfishly or obligated by family.

> "My kidney donation had nothing to do with altruism. It was a family obligation. I never 'felt good,' but that's the way it is." *(LRD)*

> "Giving my husband a kidney was a purely selfish thing to do. I wanted our life back. I wanted my husband to live the full life we had before his health went bad." *(LURD)*

Theme 4. Questions regarding the donor's emotional expectations post-donation (*n*=11). Theme four reflects suggested questions that encouraged more thought regarding the donor's expectations of the recipient, of their family and friends, and of their well-being post-donation. For example:

> "Do you expect the recipient of a gift to show appreciation or gratitude?" *(LRD)*

> "Have you ever regretted giving a gift to someone?" *(LURD)*

> "How do you expect to be treated by the hospital or by your family post-donation?" *(LRD)*

Theme 5. Questions regarding the financial and long-term health cost to the donor (*n*= 10). Theme five emerged from a number of responses suggesting questions about the donor's ability to financially afford the recovery process post-donation. For instance,

> "Are you able to give the time and money needed to recuperate from the surgery?" *(LRD)*

"Are you willing to risk your long-term health?" *(LURD)*

Theme 6. Questions will not capture the true motivation. The decision to donate comes without hesitation (*n*= 8). A number of responses suggested that no survey is necessary because people "just know" that they are going to donate their organ. The following responses illuminate this perspective:

> "I was a donor and I do not think any of these questions were relevant to my decision. I never hesitated on the decision while others refuse. It's personal." *(LRD)*

> "I recognize that it is crucial to determine the intent of a potential organ donor, but…I feel there is a large leap between impressions of an individual and the decision to be a donor. Being a donor was the easiest decision I ever made." *(LRD)*

Theme 7. No more questions are needed (*n*=6). Several responses indicated that no more questions were needed in this survey in order to assess the altruism of living kidney donors.

> "You covered them all." *(LRD)*

> "No more questions that I can think of. It seems like you have covered it all." *(LURD)*

Chapter 5: Discussion

Psychological altruism is conceptualized in the social science literature as comprised of five core components: 1) the act is ultimately motivated to benefit the other even if there are positive, unintended consequences, to the actor, 2) the act involves a sacrifice or cost to the actor, 3) the act is motivated by empathy, 4) the act is intentional, and 5) the act is beyond the actor's culturally socialized role or duties. Yet scholars continue to debate whether altruism exists and the extent to which various tools are reliable and valid in measuring altruistic motivation. There is not a consensus about altruism's existence and about a tool that consistently measures an individual's altruism. It is important to understand what role altruism plays in living organ donors. Therefore, the present study sought to investigate the prevalence of altruism among living kidney donors as measured by three independent surveys from extant literature. Further, this study compared living related donors (LRD) and living unrelated donors (LURD) to the "standard population" on which the survey scales were normed. In addition, this study investigated whether the three surveys could be combined to create a singular measure of altruism, and if so, what survey items best predict altruism among living kidney donors.

A representative random sample of 253 kidney donors from the University of Minnesota Renal Disease and Hypertension Donors list were invited to participate in a survey. One hundred sixty-eight individuals completed the survey comprised of 3 independent scales designed to measure altruism. Descriptive statistics and chi-squared analyses were used to describe the sample, and t-tests were used to compare LRDs and LURDs to the standard population on which the surveys were normed. Factor analysis

was used to determine which items from the surveys best predict altruism among living kidney donors. In the following sections major results are discussed, followed by study strengths and limitations, and future practice, policy and research directions.

Prevalence of Altruism among Living Kidney Donors

According to both the Helping Attitudes Scale (HAS) and the Self-Report Altruism Scale (SRAS), the present sample of living kidney donors are significantly more altruistic than the general population. The normative data for the HAS were obtained in from sample of 409 undergraduate students (Nickell, 1998). Other researchers have administered the HAS used in other studies assessing helping attitudes among dementia caregivers in New Zealand (Dulin and Dominy, 2008), and among non-blood donors in the U.K. (Lemmens et al., 2009). These studies did not provide a mean score on the HAS for their samples, but instead provided correlations between helping attitude and another construct. Therefore, we are unable to assess if our sample of living kidney donors are more or less altruistic than dementia caregivers in New Zealand and non-blood donors in the U.K.

Normative data from the SRAS were initially gathered through studies of 611 undergraduate students in Canada. Since then, the scale has been used in many studies (Brown et al., 2003; Eisenberg et al., 1999; Mehu et al., 2007; Otto & Bolle, 2011; Smith & Shaffer, 1986), including a study assessing if women kidney donors were more likely than men to: a) display gender-typed nurturing behavior and altruism, and b) be more influenced by family pressure to donate and less able to resist this pressure (Achille et al., 2007). Results showed no difference between women and men in their altruism scores. In

addition, the SRAS has been translated into Hindi and Chinese and adapted for youth. Normative data on the Hindi SRA-scale (Khanna et al., 1993) show higher mean altruism scores than normative data on the English SRA-scale (*M*=73.4*, SD*=12, *N*=100*)* and higher mean altruism scores than the present study's sample of living kidney. The Chinese version of the SRAS (C-SRA scale; Chou, 1996) and the Adapted SRAS, revised for youth (Rushton et al., 1981) have been developed, but there are no published normative data for these scales.

As the average age of an undergraduate student in the U.S. is 22 years (National Center for Education Statistics, 2014) the differences found in altruism scores might be attributed to the 18-year difference in average ages between the normative samples for the on HAS and SRAS (average age = 22) and the present study's sample of living kidney donors (average age = 40). For example, developmental psychologists, such as Erikson (1959), suggest there are great differences between the young adulthood stage of a 22 year old and the middle adulthood stage of a 40 year old. Specifically, Erikson posits a 22 year old is focused on love and their ability to form intimate, reciprocal relationships. A 40 year old, on the other hand, is concerned with care and their ability to make their life count. The phase is characterized by contributing to society and helping to guide future generations; a phase within which the act of donating one's kidney seems to fit. Further study of the HAS and SRAS is necessary in order to understand the effects of age, in addition to the effects of culture and gender on helping attitudes. Relatedly, research is warranted that compares scores of living kidney donors to those of normative samples of older adults.

Comparison of Related and Unrelated Donors in their Degree of Altruism

There were no statistically significant differences in altruism scores between living related donors and living unrelated donors. These findings are relevant in assessing the various ethical considerations of a living kidney donor: donor's competence, capacity to give free (non-coerced) and informed consent, and the voluntary nature of their organ donation. There is great concern in the medical community that LRDs' decision-making capacity may be compromised by family pressure, and/or social and cultural role and obligations (Landolt et al., 2001; Spital, 2001; Roff, 2007). With no significant differences in level of altruism between LRDs and LURDs in this study, it may be that the motivation to donate a kidney does not differ substantially between LRDs and LURDs. Further qualitative studies assessing other factors contributing to a donor's motivation and decision to donate are needed.

Factors that Best Predict Altruism Among Living Kidney Donors

Factor analysis of responses to items that best predicted altruism among living kidney donors in the present study yielded an underlying 4-factor conceptual structure defined below (also See Table 4). These four factors reflect the five core components extracted from the social science literature on psychological altruism, suggesting content validity of the model. That the analysis produced four rather than five factors suggests living kidney donors may view the essential components of the altruism underlying kidney donation differently than others view the altruism of heroes or rescuers or people who donate to charity. One study is insufficient to completely validate or undermine the

structure of the model, yet the results of the study indicate further investigation of these factors is needed and may result in refinement of the model.

The first factor, *Physical help to stranger,* contains seventeen scale items (all items from the SRAS) that indicate direct and physical aid from respondent to a stranger (e.g., "I have offered to help a handicapped or elderly stranger across the street," and "I have made change for a stranger"). Many of the factor one scale items correspond to these core components of psychological altruism: *The act is ultimately motivated to benefit the other even if there are positive, unintended consequences, to the actor,* and *The act is intentional* (Batson et al., 2002; Flynn & Black, 2010). This factor signifies that the aid given is a concrete action and that it was purposeful in primarily helping another person.

The second factor, *Gifts*, contains nine scale items (all items from the AGGB) that relate to a person's relationship with gift giving (e.g., "Carefully selecting and giving gifts is an important tradition for me," and "I almost always try to give gifts that convey a very personal message to the receiver"). These items relate to the core component of psychological altruism labeled: *The act is beyond the actor's culturally socialized role or duties.* While Levine et al. (2001) conceptualize gift-giving as extending beyond one's obligated role or duty, it could be argued that gift giving practices are *embedded* within one's culturally socialized role or duties. Miller et al. (2011) conducted three cross-cultural studies between U.S. and Indian adults investigating their perceptions of choice and agency in helping friends and family versus helping strangers. They found that social expectations to help family and friends tended to be more fully internalized among

Indians than among Americans. More study is needed to consider how cultural values and social expectations relate to altruism.

The third factor, *Volunteerism rewards,* contains thirteen survey items (eleven items from the HAS and two items from the SRAS) that describe the psychological and/or emotional rewards of helping another person (e.g., "It feels wonderful to assist others in need," and "Volunteering to help someone is very rewarding"). These items seem similar to: *The act is motivated by empathy*, a core component of psychological altruism (Sorokin, 1950; Batson et al., 2002). While the scale items do not assess the motivating factor behind the action, the scale items share the quality of emotional and psychological tone that is evoked by "empathy."

The fourth factor, *Risk/ sacrifice in helping*, contains nine survey items (all items from the HAS) indicating some potential risk or sacrifice to actor for their action of helping another person (e.g., "If the person in front of me in the check-out line at a store was a few cents short, I would pay the difference," and "If possible, I would return lost money to the rightful owner"). These items describe a loss or a cost to the actor for their action. In both examples, the actor loses money they otherwise would retain if they did not make the action. While there is a range of "risks/ sacrifices" between "a few cents" and "one of your body's organs," this factor appears to reflect the component of risk or sacrifice involved in psychological altruism.

While the literature distinguishes everyday altruism (returning lost money) from extreme altruism (risking one's live to save another), Rand and Epstein (2014) provided evidence that when extreme altruists explain why they decided to help, the cognitive

processes they describe are as overwhelming intuitive, automatic and fast as everyday altruism. These findings align with theoretical predictions of the Social Heuristics Hypothesis (Rand et al., 2014), which suggests extreme altruism may result from internalizing (and subsequently overgeneralizing) successful behavioral strategies from lower-stakes settings where helping is typically advantageous. This leads to the development of helping as an automatic default, which then sometimes gets applied in atypical settings where helping is extreme costly, such as risking one's life to help another.

While there were only three scale items that did not load onto any of the four factors (two items from the AGGB and one from the HAS), the items from the HAS and the SRAS contributed much more to the factors that were significant predictors of LRD vs. LURD reviewed in the following section.

Results of logistic regression.

There were three significant predictors of LRD vs. LURD: 1) Factor three, *Volunteerism rewards*; 2) Factor four, *Risk/sacrifice in helping* and 3) age. For every 1-point increase in factor 3, the donor is about 1.95 times less likely to be in LURD. In other words, the more reward potential for donation, the less likely the donor will be unrelated. The subject of reward, whether in the form of payment, incentives, or any benefit for living donation is a highly controversial topic. Some experts believe that any reward will have negative consequences leading to commercialization and would undermine altruistic efforts (Epstein, 2009). For donors, this finding could mean that if they consent to the rewards of their donation, they undermine the altruism of their gift.

This researcher was advised by a consulting nephrologist to not offer a "reward" for participation in this study, as is common practice among researchers, because this population of living donors would likely not participate if there was a direct "reward."

Interestingly, Ghahramani et al. (2013) conducted an international survey of nephrologists' perceptions about rewards for kidney donation. They found that nephrologists from India/Pakistan and the Middle East had more favorable views about rewards, while respondents from Latin America and Europe, older than 50, female nephrologists and those practicing in rural areas had less favorable views. While these findings might be explained by a multitude of cultural and socioeconomic variables present in each region, replicating this international study about perceptions of rewards among living kidney donors would provide much insight into this issue.

For every 1-point increase in Factor 4, the donor is about 4.14 times more likely to be in LURD, with all else being equal. When the risk or sacrifice increases, why is the donor more likely to be unrelated? Mikulincer and Shaver (2001, 2003, 2005) suggest it is because unrelated donors do not have the attachment security of genetics or the bond of blood relations. Living donation for an unrelated person, therefore, might assume the role of attachment security: you now have my kidney; we are now more securely connected.

For every year older a donor becomes, s/he is ~11% more likely to be in LURD, with all else being equal. These results are consistent with studies comparing demographic characteristics, including age, of LRDs and LURDs (Binet, 1997; Henderson et al., 2003; Roff, 2007; Simmons et al., 1987; Dew et al., 2012). These results are also consistent with Erikson's proposed phases of identity and roles within the

life cycle; middle-and-older adults have a greater psychological need to "give back to society" and "leave a legacy" than do younger adults (1959, p.26). Kidney donation, in this sense, may serve as a concrete and physical way to contribute meaningfully to society and leave behind a part of oneself, literally.

Respondents' Perceptions Regarding the Assessment of Altruism

Respondents' qualitative responses provide some insight regarding survey items they felt were not relevant to living donation as well as additional questions they believed should be asked on a survey assessing a potential donor's altruism.

Three of the HAS items were mentioned by at least 25% of the respondents as not relevant to living donation: "I dislike giving directions to strangers who are lost"; "I donate time or money to charities every month"; and "I rarely contribute money to a worthy cause." All three items loaded onto factor three, *Volunteerism rewards*. The first and third items are reverse-scored and their position ("dislike" and "rarely") may have confused respondents. The second item includes a statement that participants may endorse ("I donate time or money to charities"), but they might disagree with the frequency ("every month") for which because their behavior might be less frequent. Furthermore, this item may rule out people with limited incomes, but a "helping attitude." Future researchers may wish to consider excluding these items from analysis.

One item on the SRAS was noted by at least 25% of the respondents as not being relevant: "I have given a stranger a lift in my car." This item loaded onto factor one, *Physical help to stranger*. The language of "giving a lift" is not common and may have been misunderstood. Beyond that, in this day and age, the activity of inviting a stranger

into one's car is heavily advised against because of the considerable risk it poses. Furthermore, a "stranger needing a lift" seems like an ambiguous event; it is unclear how a respondent would discern that a stranger actually needs help in every situation. Future researchers may wish to consider excluding this items from analysis.

One item from the AGGB was endorsed by at least 25% of the respondents as not relevant: "I almost never give gifts to people unless it is for a special occasion or holiday." This item did not load onto any factors and was discarded. Similar to the reverse-scored items in the HAS, this item may have confounded participants because of its contradictions ("almost never") and ("never…unless").

The total number of items that were mentioned by at least 25% of respondents as not relevant include three from the HAS, one from the SRAS, and one from the AGGB. There were items that no one mentioned as not relevant: three items from the HAS ("Helping friends and family is one of the great joys in life;" "I plan to donate my organs when I die with the hope that they will help someone else live;" and "I feel at peace with myself when I have helped others") and one item from the AGGB ("Carefully selecting and giving gifts is an important tradition for me").

Additionally, their open-ended comments about additional unasked questions revealed six themes (and an additional "no more questions needed" theme). The most prevalent theme was "Questions regarding the donor's cultural ideas of giving," which relates to Factor 2: *Gifts*. Monroe's (1996) work investigated how cultural influences shape altruists' sense of the world and their relations to others. She found that none of the traditional sociocultural characteristics (age, gender, education, religion, socioeconomic

status, early childhood experience) predicted altruistic behavior. Instead, Monroe found the factor that did relate strongly to altruism was a "common perception of themselves as individuals strongly linked to others through a shared humanity" (1996, p.147).

A more recent study investigated the motivation of non-directed donors and found that their unifying culture might be "feelings of well-being." Brethel-Haurwitz and Marsh (2014) investigated non-directed kidney donation in all 50 states, cross-referencing donations with data on each state's levels of "well-being," which refers to people's levels of life satisfaction, emotional health, physical health, healthy behavior (e.g., exercise, diet), job satisfaction, and ability to meet their basic needs (e.g., food and safety). They found that states with high levels of well-being tended to have higher rates of non-directed kidney donation. Even when controlling for key factors such as education, race, age, income, and religiosity, the researchers found that a state's level of well-being still significantly predicted donation rates. Furthermore, analyses combining states into larger geographic regions confirmed that as well-being increases, so do rates of kidney donation to strangers. Moreover, as altruistic kidney donation happens relatively rarely, the researchers were able to rule out the possibility that these altruistic acts caused widespread increases in happiness rather than the other way around.

So while prior research has suggested that performing altruistic acts fosters feelings of happiness (Dew et al., 2012), the Brethel-Haurwitz and Marsh (2014) adds a new twist: a culture of happiness might actually spur extraordinary acts of altruism. More research is needed to examine the altruistic and gift giving tendencies of particular cultures (grouped by traditional sociocultural characteristics) compared to the culture of

people with the cognitive orientation of shared humanity and the culture of people who share high subjective feelings of well-being.

The next most common themes were "Questions regarding how much risk and discomfort one is willing to endure for another" and "Questions regarding the financial and long-term health cost to the donor." Both of these themes relate to Factor 4: *Risk/ sacrifice in helping.* Oliner and Oliner (1988) found that people who risked the most and endured the most cost to help another were often motivated to act because they learned care, compassion and social responsibility from their parents' values.

Fourteen respondents provided comments advising more questions regarding "Personal family obligation or selfish motivation." A smaller portion of responses recommended, "Questions regarding the donor's emotional expectations post-donation," Relating to factor 3: *Volunteerism rewards.* While these themes are related, there seem to be two distinct categories of responses within them: emotional coercion from family members to donate, and a selfish motivation to have more time left with a loved one. Regarding the latter, some literature posits that altruism does not exist; the motivation to donate one's kidney is egotistic at best, and psychopathological at worst (Oakley, 2011; Roff, 2007; Sadler et al., 1971;). A number of participants in the present study mentioned that, in fact, their motivation for donation was "selfish." There is clear evidence that helping behavior is not always guided by other-oriented, altruistic motives, but can also be governed by egoistic motives, such as enhancing one's own mood, relieving one's own distress, and protecting one's personally valuable close relationships (Cialdini et al., 1987; Cialdini et al., 1997).

For example, Binet et al. (1997) discussed the person of the LURD and discovered, in their sample of 46 donors, of whom over 90% of LURDs were the spouse or partner of the recipient. In this sense, donors are not unconcerned bystanders when their partner has terminal renal failure and when they share a common daily life. The restraints imposed by diet and dialysis, and the reduced professional possibilities of someone with end-stage renal disease (ESRD) all influence the well-being of the healthy partner. From this point of view, a successful transplantation egotistically increased the quality of life for the donor as well as the recipient. A number of LURD participants from the present study shared this point of view; one commented: "Giving my husband a kidney was a purely selfish thing to do. I wanted our life back." Another said: "I do not believe altruism is an important factor in kidney donation. Some of us selfishly want more time with a friend or family member." Interestingly, Binet et al. (1997) found that the psychological outcome for the egotistically motivated LURD significantly changes if their kidney fails in the recipient. In these instances, many LURDs feel disappointed, regret their decision to donate, and deteriorate psychologically.

More research is needed to provide a better understanding of the association between caregiving behaviors and egoistic motives for helping. Topics for investigation include the extent to and under what conditions egoistic motives lead to effective helping, and the extent to which and under what conditions egoistic motives lead to more damage.

The second component of this theme involves concern about family coercion. In this sense, Factor 3: *Volunteerism rewards,* might expand to include a broader spectrum: *Volunteerism consequence: Coercion rewards; Coercion consequences.* This concern of

LRD participants ("Did family pressure play a significant part in your decision to donate?" and "My kidney donation had nothing to do with altruism. It was a family obligation. I never 'felt good,' but that's the way it is.") is echoed in the literature. While living related organ donors may be fully competent, their decision-making capacity may be compromised by their attachment security, social/ family pressure, the cultural context, and/or other circumstances (Landolt et al., 2001; Mikulincer & Shaver, 2005; Roff, 2007; Spital, 2001).

In a Swiss study of LURDs, the majority of whom were the recipient's the spouse/ partner, 55% reported that the consultant nephrologist made the suggestion about donation, 30% spontaneously came to the idea on their own that they would donate, while the remaining 15% learned about living donation through the media; no donor was primarily asked by the potential recipient (Binet, 1997). A Spanish study found that 86% of living donors informed the recipient about their wish to donate, while the other 14% were asked by family members (Cabrer et al., 2003). A Canadian study found that only 40% of potential recipients thought it was appropriate to ask a family member or loved one to donate their kidney (Zimmerman et al., 2006). While it is globally recognized that there is lack of available kidneys, future research would benefit from investigating the question: Whose responsibility is it to find kidneys? And if the pressure to find a kidney was lifted off the recipient and their family, might the concern over voluntariness and autonomy decrease?

The final theme, "Questions will not capture the true motivation. The decision to donate comes without hesitation," does not readily reflect any of the four factors

identified in the factor analysis. The theme is, however, generally supported by findings from other studies. For example, Rand and Epstein (2014) examined the testimony of Carnegie Hero Medal Recipients, who all risked their lives to save others and found recipients' decisions to help were significantly dominated by intuition and more intuitive than a set of control statements describing deliberative decision-making. These findings remained true even when the researchers took into account that the medal winners had enough time to think before they acted, suggesting the gut-level decision overrode any deliberative process. Taken together, these findings reveal how extreme acts of altruism might be motivated by deeply rooted, even instinctive, psychological processes.

Study Strengths and Limitations

Though the study included a representative random sample of living kidney donors, it was cross-sectional, correlational and without a control group. Therefore, no causal connections can be made between the variables measured. The factor analysis accounted for 34.3% of the variance in altruism scores. Although this is a large percentage for a study of this sample size, another 65% of the variance could not be explained.

A limitation of the study concerns a clerical error of listing incorrect response options for the third scale in the survey, the Altruism and Gift Giving Battery. The response categories were incorrectly listed as "Never, Once, More than Once, Often and Very Often." The correct response categories are: "Strongly disagree, Disagree, Neither agree nor disagree, Agree, Strongly agree." As the internal consistency reliability of the scale, with the incorrect response options, was still high, $\alpha = .84$, the responses were

included in the analyses. Furthermore, additional statistical analyses were run without the third scale and no significant differences were found. The results should be interpreted carefully, however, given this error, and another study using the scale with the correct response options should be conducted.

In addition, since all the surveys were formatted with the three independent surveys in the same sequence, there could have be an order effect that influenced the findings. Order bias could be controlled for by randomly sequencing of the three independent surveys in future studies. Another limitation in using surveys is response bias. Since the topic surveyed was altruism, participants may be motivated to present themselves more favorably than is accurate. An opt-out choice ("Not sure") for every survey item might control for this type of social desirability response bias.

Finally, measurement bias, due to the language of certain survey items may have influenced results. For example, "I donate my time or money to charities every month" may rule out people with limited incomes and/or those who donate time or money, but not every month. "I have helped push a stranger's car that was down or out of gas"; this item may pull for male respondents' endorsements because it is likely more male respondents would have the physical strength as compared to female respondents. "I have given a stranger a lift in my car"; in addition to the ambiguous and confusing language of giving a "stranger a lift," the risk inherent in the act may pull for people who live in smaller towns compared to those who live in larger cities. Finally, the SRAS uses the word "stranger" in each item (Rushton et al., 1981). "Stranger" may hold negative connotation as "not friend," or as "outsider." Future studies should investigate how

"stranger" is perceived by living donors who tend towards an orientation of "we're all related." Also researchers might consider replacing "stranger" with a more neutral term.

Future Policy, Practice, and Research Directions

The question remains: "What to do about the kidney shortage?" Medical doctors, ethicists, social workers and policy makers are contemplating various solutions including: exchanging one's kidney for life-time health care, or a lump sum of money, or preference on the kidney waiting list. Another solution to bridge the supply and demand gap is to increase living kidney donation. If living kidney donation is to increase, it is important to make the possibility of offering one's kidney known with substantial evidence-based medical and psychological research.

Future research should replicate this study to confirm that the factors of *volunteerism rewards, risk/sacrifice,* and *age* are the strongest predictors of altruism in living kidney donors. In addition, future psychological research could connect with marketing/ policy research in how to utilize the results from this study to reach people who are "altruistically-oriented."

Additionally, a unique population of kidney donors is "nondirected donors," those who give their kidney without designating a recipient. The present sample contained five such donors, a number too small to use as an independent group in the data analyses. Therefore, the five non-directed donors were grouped as living unrelated donors. One of these five donors provided a comment on their survey that, "Unless I knew of the need, I wouldn't have known that I could donate." There has been remarkably little publicity or solicitation of nondirected donation since it was first conceptualized by Matas et al. in

2000. This type of donation and its social value could be announced, promoted and celebrated widely. Future research should be done to investigate the motivations, cultural orientation, and profiles of nondirected donors in order to increase this type of donation. And, as Brethel-Haurwitz and Marsh (2014) proposed, researchers might investigate policies that promote well-being as a way to generate a *virtuous circle*, whereby increases in well-being promote altruism that, in turn, increases well-being. Such a cycle holds the promise of creating a culture of well-being with broad benefits for altruists, their beneficiaries, and society at large.

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Appendix A: IRB Approval

irb@umn.edu <irb@umn.edu>
To: mclau113@umn.edu
TO : matas001@umn.edu, ibrah007@umn.edu, veach001@umn.edu, ewigx005@umn.edu, bergl175@umn.edu, mclau113@umn.edu,
Monday, November 3, 2014

The IRB: Human Subjects Committee determined that the referenced study is exempt from review under federal guidelines 45 CFR Part 46.101(b) category #2 SURVEYS/INTERVIEWS; STANDARDIZED EDUCATIONAL TESTS; OBSERVATION OF PUBLIC BEHAVIOR.

Study Number: 1410E54425

Principal Investigator: Michaela McLaughlin

Title(s):
An Investigation of the Role of Psychological Altruism in Living Kidney Donors

This e-mail confirmation is your official University of Minnesota HRPP notification of exemption from full committee review. You will not receive a hard copy or letter.

This secure electronic notification between password protected authentications has been deemed by the University of Minnesota to constitute a legal signature.

The study number above is assigned to your research. That number and the title of your study must be used in all communication with the IRB office.

Research that involves observation can be approved under this category without obtaining consent.

SURVEY OR INTERVIEW RESEARCH APPROVED AS EXEMPT UNDER THIS CATEGORY IS LIMITED TO ADULT SUBJECTS.

This exemption is valid for five years from the date of this correspondence and will be filed inactive at that time. You will receive a notification prior to inactivation. If this research will extend beyond five years, you must submit a new application to the IRB before the study's expiration date.

Upon receipt of this email, you may begin your research. If you have questions, please call the IRB office at (612) 626-5654.

You may go to the View Completed section of eResearch Central at http://eresearch.umn.edu/ to view further details on your study.

The IRB wishes you success with this research.

Appendix B: Survey Invitation via Email

Dear Insert Name:

We are very excited to share with you that the University of Minnesota Comprehensive Follow-up of Living Donors study is collaborating with Mica McLaughlin, doctoral student in counseling psychology, to explore altruism and its impact on your decision to become a living kidney donor. We understand the decision to donate is a complicated one however the intent of this project is to look in depth at one aspect (altruism) to improve our understanding for future donors.

If you decide to participate, please read the attached consent statement then follow the link below to complete the survey on-line. In order to allow adequate time to analyze the responses please complete the survey **no later than November 30, 2014**. This is a one-time survey however if you are a participant in the Comprehensive Follow-up of Living Donors study, you will continue to hear from us every 3 years.

<<LINK TO WEB SURVEY>>

Your participation in this project is voluntary and refusing to participate will not affect your relationship with this ongoing living donor study or the University of Minnesota. If you do not wish to participate we ask that you contact any of the numbers below or simply reply to this email stating you decline at this time.

If you have any questions and would like to speak with someone directly involved with this project we encourage you to contact:

Mica McLaughlin, PhD candidate, 651-328-9777, mclau113@umn.edu
Danielle Berglund, study coordinator, 612-626-2506, tisdonor@umn.edu

We are looking forward to hearing from you. Thank you for your time and effort.

Sincerely,

Arthur J. Matas, MD
Professor of Surgery
Director, Renal Transplantation

Appendix C: Survey Invitation via Mail

UNIVERSITY OF MINNESOTA

Transplant Research Organization

150 Dinnaken Bldg.
925 Delaware St. SE
Minneapolis, MN 55414
Office: 612-626-2506
Fax: 612-624-0902

November 1, 2014

Donor Name
Address
City, State Zip

Dear Insert Name:

We are very excited to share with you that the University of Minnesota Comprehensive Follow-up of Living Donors study is collaborating with Mica McLaughlin, doctoral student in counseling psychology, to explore altruism and its impact on your decision to become a living kidney donor. We understand the decision to donate is a complicated one however the intent of this project is to look in depth at one aspect (altruism) to improve our understanding for future donors.

If you decide to participate, please read the consent statement. Once you have completed the survey, you may return it in the postage paid envelope included with this letter. In order to allow adequate time to analyze the responses please return the survey **no later than November 30, 2014**. This is a one-time survey however if you are a participant in the Comprehensive Follow-up of Living Donors study, you will continue to hear from us every 3 years. Your participation in this project is voluntary and refusing to participate will not affect your relationship with the ongoing living donor study or the University of Minnesota. If you do not wish to participate we ask that you contact any of the numbers below or return the bottom half of this letter by mail using the included return envelope.

If you have any questions and would like to speak with someone directly involved with this project we encourage you to contact:

Mica McLaughlin, PhD candidate, 651-328-9777, mclau113@umn.edu
Danielle Berglund, study coordinator, 612-626-2506, tisdonor@umn.edu

We look forward to hearing from you.

Sincerely,

Arthur J. Matas, MD
Professor of Surgery
Director, Renal Transplantation

……✂……

☐ I do not wish to participate in Mica McLaughlin's "An Investigation of the Role of Psychological Altruism in Living Kidney Donors" project.

NAME: _____

Date:_____

Appendix D: Survey

Altruism & Kidney Donation

Comprehensive Follow-up of Living Donors Study

University of Minnesota

Instructions:

1. **Altruism is the selfless concern for the well-being of others.** We would like to see if surveys designed to assess altruism in the general population apply to donors like you. Creating a survey that is more specific to kidney donors is our ultimate goal.
2. **Mark ☒ for the answer that best fits how you would have responded around the time you donated your kidney.**
3. Your answers will only be viewed by Michaela McLaughlin, PhD candidate, for data entry purposes.
4. Return the survey in the postage paid business reply mail envelope or the address listed at the end of the survey.
5. **Kindly return this survey no later than November 30, 2014**

SURVEY #1

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
1. If possible, I would return lost money to the rightful owner	1☐	2☐	3☐	4☐	5☐
2. I would avoid aiding someone in a medical emergency if I could	1☐	2☐	3☐	4☐	5☐
3. Helping friends and family is one of the great joys in life	1☐	2☐	3☐	4☐	5☐
4. I try to offer my help with any activities my community or school groups are carrying out	1☐	2☐	3☐	4☐	5☐
5. Volunteering to help someone is very rewarding	1☐	2☐	3☐	4☐	5☐
6. I rarely contribute money to a worthy cause	1☐	2☐	3☐	4☐	5☐
7. Doing volunteer work makes me feel happy	1☐	2☐	3☐	4☐	5☐
8. Unless they are part of my family, helping the elderly isn't my responsibility	1☐	2☐	3☐	4☐	5☐
9. When given the opportunity, I enjoy aiding others who are in need	1☐	2☐	3☐	4☐	5☐
10. Children should be taught about the importance of helping others	1☐	2☐	3☐	4☐	5☐
11. I dislike giving directions to strangers who are lost	1☐	2☐	3☐	4☐	5☐
12. I donate time or money to charities every month	1☐	2☐	3☐	4☐	5☐
13. I plan to donate my organs when I die with the hope that they will help someone else live	1☐	2☐	3☐	4☐	5☐
14. Helping others is usually a waste of time	1☐	2☐	3☐	4☐	5☐
15. I feel at peace with myself when I have helped others	1☐	2☐	3☐	4☐	5☐
16. If the person in front of me in the check-out line at a store was a few cents short, I would pay the difference	1☐	2☐	3☐	4☐	5☐
17. I feel proud when I know that my generosity has benefited a needy person	1☐	2☐	3☐	4☐	5☐

18. Helping people does more harm than good because they come to rely on others and not themselves	1☐	2☐	3☐	4☐	5☐
19. It feels wonderful to assist others in need	1☐	2☐	3☐	4☐	5☐
20. Giving aid to the poor is the right thing to do	1☐	2☐	3☐	4☐	5☐

This is the end of Survey #1

21. Do you feel **Survey #1** would determine whether someone interested in being a living kidney donor is altruistic?

Yes 1☐ No2☐

22. Which question(s) in **Survey #1** do you feel are not relevant to living donation? *(Indicate the question # in the space below)*

_____

_____

SURVEY #2

	Never	Once	More than once	Often	Very Often
1. I have helped push a stranger's car that was broken down or out of gas	1☐	2☐	3☐	4☐	5☐
2. I have given directions to a stranger	1☐	2☐	3☐	4☐	5☐
3. I have made change for a stranger	1☐	2☐	3☐	4☐	5☐
4. I have given money to a charity	1☐	2☐	3☐	4☐	5☐
5. I have given money to a stranger who needed it (or asked me for it)	1☐	2☐	3☐	4☐	5☐
6. I have donated goods or clothes to a charity	1☐	2☐	3☐	4☐	5☐
7. I have done volunteer work for a charity	1☐	2☐	3☐	4☐	5☐
8. I have donated blood	1☐	2☐	3☐	4☐	5☐
9. I have helped carry a stranger's belongings (books, parcels, etc).	1☐	2☐	3☐	4☐	5☐
10. I have delayed an elevator and held the door open for a stranger	1☐	2☐	3☐	4☐	5☐

11. I have allowed someone to go ahead of me in a lineup (in the supermarket, at a copy machine, at a fast-food restaurant).	1☐	2☐	3☐	4☐	5☐
12. I have given a stranger a lift in my car	1☐	2☐	3☐	4☐	5☐
13. l have pointed out a clerk's error (in a bank, at the supermarket) in undercharging me for an item	1☐	2☐	3☐	4☐	5☐
14. I have let a neighbor whom I didn't know too well borrow an item of some value to me (eg, a dish, tools, etc)	1☐	2☐	3☐	4☐	5☐
15. I have bought 'charity' holiday cards deliberately because I knew it was a good cause	1☐	2☐	3☐	4☐	5☐
16. I have helped a classmate who I did not know that well with an assignment when my knowledge was greater than theirs	1☐	2☐	3☐	4☐	5☐
17. I have, before being asked, voluntarily looked after a neighbor's pets or children without being paid for it	1☐	2☐	3☐	4☐	5☐
18. I have offered to help a handicapped or elderly stranger across a street	1☐	2☐	3☐	4☐	5☐
19. I have offered my seat on a bus or train to a stranger who was standing	1☐	2☐	3☐	4☐	5☐
20. I have helped an acquaintance to move households	1☐	2☐	3☐	4☐	5☐

This is the end of Survey #2

21. Do you feel **Survey #2** would determine whether someone interested in being a living kidney donor is altruistic?

Yes 1☐ No2☐

22. Which question(s) in **Survey #2** do you feel are not relevant to living donation? *(Indicate the question # in the space below)*

SURVEY #3

	Never	Once	More than once	Often	Very Often
1. I show my friendship to others by giving them special gifts occasionally	1☐	2☐	3☐	4☐	5☐
2. I almost always exert considerable effort to select or make special gifts for close members of my family	1☐	2☐	3☐	4☐	5☐
3. I almost never give gifts to people unless it is for a special occasion or holiday	1☐	2☐	3☐	4☐	5☐
4. Carefully selecting and giving gifts is an important tradition for me	1☐	2☐	3☐	4☐	5☐
5. I generally give gifts because people expect me to give them	1☐	2☐	3☐	4☐	5☐
6. I almost always try to give gifts that convey a very personal message to the receiver	1☐	2☐	3☐	4☐	5☐
7. I enjoy the giving of gifts more than the receiving of gifts	1☐	2☐	3☐	4☐	5☐
8. I consider myself someone who gives a lot of gifts	1☐	2☐	3☐	4☐	5☐
9. I consider gifts to be an important way of communicating love or friendship to others	1☐	2☐	3☐	4☐	5☐
10. Most of the gifts I buy seem to reflect my tastes more than the receiver's tastes	1☐	2☐	3☐	4☐	5☐
11. I try to buy gifts that reflect the receiver's tastes more than my tastes	1☐	2☐	3☐	4☐	5☐

This is the end of Survey #3

21. Do you feel **Survey #3** would determine whether someone interested in being a living kidney donor is altruistic?

Yes 1☐ No2☐

22. Which question(s) in **Survey #3** do you feel are not relevant to living donation? *(Indicate the question # in the space below)*

_____

_____

COMMENTS:

What questions do you think are important to ask but were not covered by these surveys?

(continue on the back page if needed)

_____

_____

_____

_____

Thank you for all you have and continue to do to improve knowledge about kidney donation

Please return your survey in the enclosed postage paid pre-addressed envelope or send to:

University of Minnesota
Transplant Research Office
Attn: Danielle Berglund, Study Coordinator
925 Delaware St SE, Suite 150
Minneapolis, MN 55414

Appendix E: Follow-up Phone Call Script

If Donor Answers:

May I please speak to << donor's name >>?

Hello, this is << caller's name>> calling from the University of Minnesota, Department of Surgery. I'm calling about a new survey we sent to you studying altruism and kidney donation.

Do you have a minute to talk?

NO =*Is there a better time for me to call back ?* Make an appointment. Get contact information. *Thanks again.*

YES = Continue.

You are currently enrolled in our Long-Term follow-up of Living Donors GFR study. As part of this project, we are working with doctoral student Michaela McLaughlin to study altruism and your decision to donate your kidney. About a month ago we mailed/ emailed a survey to you.

Did you receive it?

NO =*Would you like me to send another one?*

NO = *Thank you for your time. We appreciate all that you have contributed to the study of kidney donation.*

YES = *We will resend the survey. (*Confirm address/ email is current). *Thank you for your time. We appreciate all that you have contributed to the study of kidney donation.*

YES = *Are you interested in participating in this project?*

NO = *Thank you for your time. We appreciate all that you have contributed to the study of kidney donation.*

YES = *Thank you for your time. Please return the survey as soon as you are able. We appreciate all that you have contributed to the study of kidney donation.*

If Donor Does Not Answer:

This message is for <<donor's name >>. My name is Mica McLaughlin and I'm calling from the University of Minnesota Department of Surgery. You are currently enrolled in our Long-Term follow-up of Living Donors GFR study. About a month ago we mailed/ emailed a survey to you. If you are interested in participating in this project please return the survey at your earliest convenience. Should you have any questions you may contact me at 612-626-2506.

Appendix F: Qualitative Comments Regarding Additional Unasked Questions

Theme 1. Questions regarding the donor's cultural ideas of giving (*n*=20).

"As you were raised, do you have a family history of volunteering and helping others?" *(LURD)*

"Is giving a part of your religious belief?" *(LRD)*

"A little more about a person's ability to give would be an interesting factor. Also, how one was raised to believe about giving - was it a required religious belief; a tax benefit; how much was it taught to make one feel better, rather than how "community" works, or how natural giving & receiving is to being human. And conversely, how often has a person been on the receiving end of altruistic behavior- that can be a powerful learning experience." *(LRD)*

"I would ask if a person loved and liked themselves, mainly because there are people who give to feel good about themselves. It is so much better to feel good and then give."*(LRD)*

"Can you give gifts/ do favors without any strings attached? Can you totally give up control of gifts after they are given? Can your mindset go from "mine" to "yours"?" *(LRD)*

"Do you ever give a gift which you think is too costly but that you know they really want?" *(LRD)*

"Questions related to the thoughts of giving prior to the kidney donation and after."*(LRD)*

"A gift is something you give and don't expect anything in return, even if you think they don't take care of it." *(LURD)*

"Do you give to help people feel they are special?" *(LRD)*

"Why you are donating? Is it because the person who receives the kidney is special to you? Would you donate a kidney to a stranger?" *(LURD)*

"What is your motivation for donating?" *(LRD)*

"Have you ever considered "pay it forward" donation to a stranger, who then donates to a stranger who is a match, etc.?" *(LRD)*

"Do you think giving of one's time, energy and emotion far outweighs monetary giving? Do you think donating money is a sacrifice for middle income or high income

Americans? Honestly, donating money is a small token compared to volunteering time and resources and body parts." *(LRD)*

"Is your sense of self worth directly related to sharing your gifts of time and money with others?" *(LRD)*

"Who would you be willing to donate to? Who would you not be willing to donate to?" *(LRD)*

"How religious reasons impact gift giving." *(LRD)*

"I had to ask myself before deciding to donate would the person in need have done it for me and the answer was yes." *(LRD)*

"Would you ever give a part of your body (i.e. kidney) to a friend or relative in need?" *(LURD)*

"As a kidney donor, I would ask if the donor would do it again. If they had 8 kidneys, would they give away 7?" *(LRD)*

"Do you feel you were given a gift of good health and want to share that with someone in need?" *(LURD)*

Theme 2. Questions regarding how much risk and discomfort one is willing to endure for another (*n*= 17).

"Are you willing to risk your health to benefit another human being?" *(LURD)*

"Would you accept pain so someone else would not have to feel pain?" *(LRD)*

"Have you ever risked bodily harm to aid someone else?" *(LRD)*

"I am willing to experience some personal short-term pain for a possible long-term success for another?" *(LRD)*

*"*Would you consider donating a kidney to a loved one?" *(LRD)*

"How much fear people are willing to face to help another." *(LRD)*

"Questions that reflect the seriousness of the donation and kidney removal process to the donor's immediate comfort and long-term health. Virtually all of these questions were about monetary things or time; none addressed the depth of altruism required for donation. Donating a kidney means risking one's life and, possibly, one's future health (if

something happened to the remaining kidney). That's not the same as putting money in the Salvation Army kettles, though both are altruistic. Similarly, for many donors (I assume) they KNOW the person who is receiving the kidney, and the importance of that relationship is a primary motivator. So, while I might never have volunteered for or donated to a charity, the opportunity to save my brother's life might motivate me in ways more common forms of altruism do not." *(LRD)*

"If someone is going to die and you had to risk your life to help, would you?" *(LRD)*

"Would you lay down your life for a friend? Would you put a family's medical needs before your needs?" *(LURD)*

"Would you willingly donate an organ if you knew it would save someone's life?" *(LURD)*

"Have you volunteered to take on a task that no one else wanted to do?" *(LRD)*

"Would you ever give a part of your body (kidney) to a friend or relative in need?" *(LURD)*

"As a kidney donor, I would ask if the donor would do it again. If they had 8 kidneys, would they give away 7?" *(LRD)*

"Question about doing something for others that has some real cost to the giver. Giving up your seat on the bus to an elderly person is a nice thing to do, but it doesn't really cost you much to do that. Just about everyone I know would do that. But none of these friends of mine have any interest in donating a kidney. So that question (and others like it) isn't going to be a good indicator of the likelihood of someone's interest in donating a kidney. I believe, that in some sense, kidney donors care more about others than they do of themselves. See if you can come up with some questions that really get at that issue. Is someone willing to put the interests of others ahead of their own interests when there's really something at stake?" *(LURD)*

"Do what extent do I value some else's health and well-being relative to my own? What kind of risk am I willing to take to ensure the health of another?" *(LRD)*

"These questions certainly get at whether a person is caring and wants to help others, or make them feel better. However as I said earlier, it is a big step from there to consider personal risk and possible loss of quality of life or in an extreme case, loss of life." *(LRD)*

"Would you seriously consider the long term impacts on your life and family when considering donating a kidney?" *(LRD)*

Theme 3. Comments regarding personal family obligation or selfish motivation (*n*= 14).

“My kidney donation had nothing to do with altruism. It was a family obligation. I never ‘felt good,’ but that’s the way it is.” *(LRD)*

“Giving my husband a kidney was a purely selfish thing to do. I wanted our life back. I wanted my husband to live the full life we had before his health went bad.” *(LURD)*

“Questions that reflect the seriousness of the donation and kidney removal process to the donor's immediate comfort and long-term health. Virtually all of these questions were about monetary things or time; none addressed the depth of altruism required for donation. Donating a kidney means risking one's life and, possibly, one's future health (if something happened to the remaining kidney). That's not the same as putting money in the Salvation Army kettles, though both are altruistic. Similarly, for many donors (I assume) they KNOW the person who is receiving the kidney, and the importance of that relationship is a primary motivator. So, while I might never have volunteered for or donated to a charity, the opportunity to save my brother's life might motivate me in ways more common forms of altruism do not.” *(LRD)*

“Questions about what a person is obligated to do for a family member.” *(LRD)*

“Did family pressure play a significant part in your decision to donate? Was your personal relationship with the recipient a major factor in your decision to donate?” *(LRD)*

“I feel most people would not hesitate being a donor if the recipient is a family member or close friend. Do not feel like I would help people that are physically and mentally able to help themselves.” *(LRD)*

“I think there is a line of questioning to determine if you are altruistic or selfish.” *(LRD)*

“I think questions asking if you would do something for payment of some kind for a stranger or if they would do something without thinking of payment. The payment I received was having my Mother in my life for 7 more years.” *(LRD)*

“We have several organ donors in our family and the organs were to other family members so I think that is a little different (the motivation) than donating to a stranger. I know one of our donors was a rather "reluctant" donor. I'm not sure she would be considered very altruistic.” *(LRD)*

“Why you are donating? Is it because the person who receives the kidney is special to you? Would you donate a kidney to a stranger?” *(LURD)*

"I do not believe altruism is an important factor in kidney donation. Some of us selfishly want more time with a healthy friend or family member. There are many reasons people choose to donate." *(LRD)*

"I think you need to get more in depth at the difference between helping/saving a family member or close friend as opposed to an acquaintance or stranger. Ask more direct questions that get at selflessness, willingness to save the life of another person." *(LRD)*

"I donated to my daughter so there was never any question in my mind. However some others who considered donating to her seemed to back out or be relieved when they didn't match. I don't judge them for that, but I wonder how family pressure influenced them." *(LRD)*

"I gave a kidney to a friend because it was the right thing to do. Does that make me "altruistic"? I don't think so." *(LURD)*

Theme 4. Questions regarding the donor's emotional expectations post-donation

(*n*=11).

"Do you expect the recipient of a gift to show appreciation or gratitude?" *(LRD)*

"Have you ever regretted giving a gift to someone?" *(LURD)*

"How do you expect to be treated by the hospital or by your family post-donation?" *(LRD)*

"Do you ever give a gift which you think is too costly but that you know they really want?" *(LRD)*

"Do you continue to feel good about giving a gift even if the recipient does not show appreciation?" *(LRD)*

"After donation, did anyone care that you donated?" *(LRD)*

"Nothing was asked about valuing life. Nor about quality of life. If someone can get a kidney and not have to endure the emotional process of dialysis, giving them a better quality of life, that is emotionally relevant to donor." *(LURD)*

"Do you think giving of ones time, energy and emotion far outweighs monetary giving?" *(LRD)*

"I think that the survey should include some questions addressing the subject of guilt or remorse after having performed some of these activities: did you have second thoughts?" *(LRD)*

"I believe in helping others. I was very lucky so people should always help each other." *(LRD)*

"A positive attitude is the best measurement of an altruistic kidney donor." *(LRD)*

Theme 5. Questions regarding the financial and long-term health cost to the donor (*n*= 10).

"Are you able to give the time and money needed to recuperate from the surgery?" *(LRD)*

"Are you willing to risk your long-term health?" *(LURD)*

"Should ask living donors the long-term effects of donation. I experienced kidney stones, and I am a Diabetic and this has altered my treatment from my doctor." *(LRD)*

"Are you prepared to experience possibly significant health issues later in life as a result of a donation? Would you donate if it were possible that donation could limit treatment options for a medical condition later in life? *(LRD)*

"Financial questions." *(LRD)*

"Specifically about organ donation or other assistance one could provide to a donor or recipient, for example to help cook or clean or drive after surgery." *(LRD)*

"Would you seriously consider the long term financial and health impact on your life and family when considering donating a kidney?" *(LRD)*

"U of M doctors fucked-up my donation surgery and I have been terribly sick ever since that fateful day back in Sept 2002. Post donation, I lost over 25 lbs. and never recovered. It has wrecked my life and my health and I have limped along for all of these years. Too sick to work because I have been plagued with a permanent case of nausea and vomiting, severe abdominal pain and chronic weight loss. I hate the doctors and staff of U of M transplant program for the irreparable harm they have caused me. If I had to do it all over again, I wouldn't have done it. You guys suck." *(LURD)*

"Are you physically able to donate and all the time and pain one goes through when donating a organ? Are you financially able to donate by taking time off work and extra expenses in the future?" *(LRD)*

"Questions that reflect the seriousness of the donation and kidney removal process to the donor's immediate comfort and long-term health. Virtually all of these questions were about monetary things or time; none addressed the depth of altruism required for donation. Donating a kidney means risking one's life and, possibly, one's future health (if something happened to the remaining kidney). That's not the same as putting money in the Salvation Army kettles, though both are altruistic. Similarly, for many donors (I assume) they KNOW the person who is receiving the kidney, and the importance of that relationship is a primary motivator. So, while I might never have volunteered for or donated to a charity, the opportunity to save my brother's life might motivate me in ways more common forms of altruism do not." *(LRD)*

Theme 6. Questions will not capture the true motivation. The decision to donate comes without hesitation (*n*= 8).

"I was a donor and I do not think any of these questions were relevant to my decision. I never hesitated on the decision while others refuse. It's personal." *(LRD)*

"I recognize that it is crucial to determine the intent of a potential organ donor, but…I feel there is a large leap between impressions of an individual and the decision to be a donor. Being a donor was the easiest decision I ever made." *(LRD)*

"It seems these questions quite well covered the type of person to be a living donor. In my case, when given the opportunity I was a full match - there was no question or thought about whether yes or no. That's just the way it was to be. Hopefully to give my sister more time to enjoy living. 33 years so far. Just one of those things we do! Now her days are numbered (survey received by mail, difficult to read this last sentence might be incorrect). I'm doing fine - 13 yrs older than she. No regrets about giving one of my kidneys to her. She appreciated it and that is a good feeling for me. Just one of those things we do. We're all in God's hands. God bless you in your research. Hope it helps you and others." *(LRD)*

"I told my brother more than once that if I had to do it all over again I would in a heartbeat. It's the easiest choice." *(LRD)*

"The donation to me was very personal. I didn't care what anyone else thought - for it was my decision only - and didn't ask anyone's else opinion." *(LURD)*

"I don't think a survey is necessary. People know if they want to donate." *(LRD)*

"Sorry, but I thought these questions were not at all relevant to being a living kidney donor. You just know that you want to be." *(LURD)*

"I donated to my daughter so there was never any question in my mind. However some others who considered donating to her seemed to back out or be relieved when they didn't match. I don't judge them for that, but I wonder how family pressure influenced them." *(LRD)*

Theme 7. No more questions are needed (*n*=6).

"You covered them all." *(LRD)*

"No more questions that I can think of. It seems like you have covered it all." *(LURD)*

"Great survey. Thanks for including me. Nothing else needed." *(LRD)*

"Can't think of any." *(LRD)*

"Nothing, thank you!" *(LRD)*

"None." *(LURD)*

Miscellaneous. (*n*=6).

"Change the answers available in survey #3." *(LURD)*

"Entry note: Survey #3 Q3 left blank. Entered as '3'." *(LRD)*

"Most of the questions were a surprise to me. I thought the survey would be more about why a person would donate an organ. I would be interested to better understand the behaviors of positive verses negative answers to the questions, in relation to organ donation." *(LURD)*

"In survey #2 the choice of "more than once" and "often" were confusing. Many times could be "more than once" but not necessarily "often". The choices for #3 should maybe have the choices of survey #1." *(LRD)*

"I think a written response as to why a person donated a kidney may provide more personal insight. They may be hard to categorize, but would be helpful. I think people would like to share their stories. I was 22, my Dad was 48, and it was 35 years ago that I donated. I still get misty when I think about it. Good luck; thanks for including me." *(LRD)*

"I found this survey rather interesting by connecting these types of questions with an individual's decision to donate an organ. I would have never thought of connecting ones manners and beliefs on how they treat others with the decision of donating organs."*(LRD)*