

# Impression Management and Psychological Reactions of Living Kidney Donors

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IMPRESSION MANAGEMENT AND PSYCHOLOGICAL REACTIONS  
OF LIVING KIDNEY DONORS

by

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ABSTRACT  
IMPRESSION MANAGEMENT AND PSYCHOLOGICAL REACTIONS  
OF LIVING KIDNEY DONORS

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This report describes the findings of a mixed-methods study that examined the psychological reactions and use of impression management by individuals who had donated a kidney. It focused on the use of impression management and concealing information during the pre-donation psychological evaluation that is conducted to help determine the donor's appropriateness for a donation, and the psychological reactions of living kidney donors post donation. A search of the literature found no study that has empirically investigated the prevalence of impression management and concealing information by living kidney donors during their pre-donation psychosocial evaluations. The mixed methods design utilized both a quantitative phone questionnaire ( $n= 76$ ) as well as qualitative focus groups ( $n=21$ ). Many of the kidney donors reported that they used impression management in their interactions with medical professionals pre-donation as they often possessed a very strong motivation to donate. Very few donors indicated, however, that they concealed information during their pre-donation evaluations. The donors' psychological reactions post-donation were generally positive and the very large majority indicated that they had no regrets concerning donation. Some negative psychological reactions were reported, though these tended to be associated with kidney grafts that were unsuccessful.

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## CHAPTER I: INTRODUCTION

Demand for kidney organ donors began to rise in the 1960s as improvements in transplantation technology provided a viable alternative to kidney dialysis to patients who experienced kidney failure. Research indicated that live donation from close biological relatives well matched for the major human leukocyte antigens (HLA) had strong advantages over donation using cadaver kidneys. Despite the clear advantages of live kidney donation for recipients, there were concerns in the medical field that recipient benefits may overshadow the safety and well-being of donors (Surman, Fukunishi, Allen, & Hertl, 2005). These concerns were based upon a desire to do no harm to the donor and to ensure informed consent.

In the 1970s, the benefits of kidney transplantation became more evident as concerns decreased about the safety of kidney donation and the well-being of donors. The U.S. Congress legislated funds for end-stage renal disease in 1972 and the criteria for those receiving transplantation were expanded. Research also began to show that carefully selected donors could actually benefit psychologically from donation (Surman, Fukunishi, Allen, & Hertl, 2005). Public opinion began to embrace the life enhancing potential of living kidney donation. A focus on theories of justice in the bioethics field along with passage of the Americans with Disabilities Act in 1990, led to the expansion of the selection criteria for transplant recipients (Surman, Fukunishi, Allen, & Hertl, 2005). The number of organ donations rose from 5,909 in 1988 to 14,145 in 2011 (UNOS, 2011).

A substantial amount of research has been conducted on the psychological experiences of organ transplant recipients. There has been much less research, however, on the psychological experiences of living kidney donors (Young, 2007). Donating one's

kidney is a generous act; however, it may also be a potentially complicated psychological experience. Kidney donors' experiences as they consent to and proceed through the donation process, and their reactions following the donation, may have significant implications for donors and transplant treatment teams.

A better understanding of kidney donors' potential use of impression management to influence clinicians evaluating them as donor candidates, and whether these factors are related to donors' psychological reactions following the donation, may be informative to the psychosocial evaluation and the informed consent processes used for kidney donation. This information may also be helpful for improving the understanding of the motivations and experiences of living kidney donors, improving the reliability of psychosocial evaluations at transplant centers, and potentially enhancing donor outcomes. The present study was designed to address this need in the literature on kidney donation.

### **Overview of the Project**

Chapter II provides a review of the literature on impression management and the physical and psychological experiences of living kidney donors before and after donation. The chapter begins with a review of the history and context of kidney transplantation with live donors including: a discussion of the shortage of living kidney donors, an overview of the process of becoming a living kidney donor, donor outcomes, and a variety of other issues. This is followed by a review of the literature regarding the motivations of living kidney donors and the process of evaluation and selection prior to donation. This section of the literature review begins with a discussion of altruism as it relates to the living kidney donor, the motives and decision-making process of donors, and an overview of the process of donor evaluation, selection, and acceptance. The section concludes with a discussion of the level of disclosure by donors during the

evaluation. A brief review of the theory on impression management from the social psychology literature is provided before discussing the relevance of impression management in the context of evaluating living kidney donors. Chapter II concludes with a summary and discussion of the existing literature on these topics.

Chapter III describes the mixed-methods design utilized to investigate the research questions addressed in this study. These methods included both quantitative and qualitative approaches. For the quantitative portion of the study, a brief telephone survey was administered to the participants. For the qualitative portion, focus groups were conducted to explore responses to the telephone survey questions in a more in-depth forum. Chapter IV provides a detailed description of the results from the telephone survey and the focus groups. Lastly, Chapter V discusses the results and their implications for kidney transplant centers.

### **Research Questions**

The present study investigated kidney donors' use of impression management during their pre-donation evaluation to determine whether they were suitable candidates for a donation as well as their post-donation reactions and experiences. A mixed-methods design was utilized to investigate the following research questions. First, to what extent and in what ways do living kidney donors use impression management and the concealment of information during the psychosocial evaluation? Second, what are living kidney donors' psychological reactions (both positive and negative) post-donation? The study also examined the relationship between the use of pre-donation impression management and the post-donation psychological reactions of the donors.

## CHAPTER II: LITERATURE REVIEW

### The History and Context of Living Kidney Donation

#### A Brief History of Live Kidney Donation

The first successful living kidney transplant was performed in 1954 by Dr. Joseph Murray of Brigham and Women's Hospital in Boston between identical 23-year-old twins (Ronald and Richard Herrick). Murray later won the 1990 Nobel Prize in recognition of his accomplishments in the field of renal transplant (Young, 2007). In the six and one-half decades since the first renal transplantation from a living donor, live kidney donation has become a common approach to treating End-Stage Renal Disease (ESRD; Ingelfinger, 2005). Demand for kidney organs started to increase in the 1960s as developments in the science of transplantation began providing a viable alternative to hemodialysis (Surman, Fukunishi, Allen, & Hertl, 2005).

Healthy kidneys clean the blood by removing excess fluids, minerals, and wastes. In addition, they produce hormones that contribute to strong bones and healthy blood. When kidney failure occurs, harmful wastes accumulate in the body resulting in a number of unhealthy conditions including high blood pressure, fluid retention, reduced red blood cell production, and eventually death (Simmons, Klein, & Simmons, 1977; Capelle, 2009). Hemodialysis can remove these waste products from the blood, but the treatment can be inconvenient and uncomfortable. Patients are attached to a machine that filters wastes from the blood, a few ounces at a time, and then returns the cleansed blood to the patient's body. Most patients go to a clinic or dialysis center three times a week for three

to five hours each time they receive dialysis. Kidney transplantation provides a successful alternative to dialysis. Initially, transplantation was only successful when performed between relatives who had the same blood type and cross match compatibility, a circumstance that still often leads to the best recipient-donor match (Young, 2007).

During the early years of kidney transplantation, there was great skepticism in the medical community about the safety of kidney donation and the psychology of donor altruism. The medical community raised a number of ethical concerns regarding the risks and complications to donors (Surman, Fukunishi, Allen, & Hertl, 2005). In the 1970s, however, a more egalitarian perspective on kidney donation developed, and in 1972 legislation was passed to provide government funding for ESRD. The criteria for recipient transplantation candidates began to expand as research demonstrated that carefully selected donors could actually benefit psychologically from donation. Further research conducted in the 1970s and 1980s supported these general conclusions. The public perception of live donor organ transplantation became more positive and advances in immunosuppression treatment led to clinical advances in the viability of live donor kidney transplants. The criteria for donation began to expand because of growing public acceptance and medical advances, including donations from living relatives to non-biologically related patients (e.g., spouses) and eventually Good Samaritan donors who did not know the recipient prior to the decision to donate (Najarian, 2005; Surman, Fukunishi, Allen, & Hertl, 2005).

In 1995, a surgical technique was developed using laparoscopic methods to procure the kidney from the donor in a less invasive manner than open surgery. This less invasive method, called "laparoscopic nephrectomy," eventually replaced "open

nephrectomy" as the most common surgical procedure because of its advantages for the donor (Bartlett, 2002). Research suggests that the new laparoscopic technology has a more positive influence on the recipients in pursuing live donation than it does on the donors because recipients feel it is a safer procedure for the donor. The benefits of this procedure include a more rapid return to normal activity, fewer major complications, and an earlier return to work.

Kidney transplantation has become one of the most frequent types of transplant operations in the United States. Out of a total of 329,999 organ transplants since 1987, two thirds involved kidneys, and demand for the procedure has been growing (Young, 2007). In the United States, 16,026 individuals were on the national waiting list for solid organ transplants in 1988. That number increased by 302% to 64,423 in 1998. In 2004, there were 86,005 candidates on the waiting list for transplants. This number rose to over 100,000 in 2011 (UNOS, 2012). As the use of cadaveric donors cannot keep pace with the growing demand for kidneys, living donation has become a preferable alternative for many patients with ESRD (Finn, 2000; Petechuk, 2006; Young, 2007).

### **Overview of Becoming a Live Kidney Donor**

The initial steps involved in becoming a living kidney donor include agreement by the potential donor and recipient, and approval by the transplant team to facilitate a process for matching. This matching process is an attempt to identify whether the recipient will be at risk to reject the potential donor's kidney. This matching process involves the completion of a complex series of medical and psychological evaluations for both the recipient and the donor. In order to qualify as a living donor, the individual must

be in good general health and free from high blood pressure, diabetes, cancer, as well as kidney, heart, liver and lung disease. HIV and hepatitis may also disqualify a donor. As a first step in this process, a living donor must undergo a blood test to determine blood type compatibility with the candidate. If it is determined that the donor candidate and the potential recipient have compatible blood types, the next step is for the donor to undergo a medical history and complete physical examination (UNOS, 2007). The physical exam also involves tissue typing. This process examines the match of the human leukocyte antigens (HLA) between the donor and recipient. There are many different types of antigens, but there are three categories assessed for kidney donation, designated as HLA-A, HLA-B and HLA-DR. Each person inherits one set of these three types of antigens from each parent resulting in a total of six HLA's. Closer antigen matches between donors and recipients are highly preferable because recipients are less likely to reject closely matched kidneys. It should be noted that although this test is still performed at many transplant centers, it is not as crucial as it once was due to the development of more effective antirejection drugs (UNOS, 2007; "Living Donors Online," 2010).

The next test performed is called "cross matching." Cross matching involves an additional test of antigen compatibility. White blood cells from the donor are mixed with blood from the recipient. If the white blood cells are attacked and die, then a cross match is "positive." This would lessen the person's compatibility as the recipient would be "sensitized" to the donor organ and attempt to destroy it. A negative cross match, however, indicates that a donor is compatible with a recipient ("UNOS pamphlet," 2007; [www.livingdonorsonline.org](http://www.livingdonorsonline.org)).

If the cross matching is negative, the next test performed is an anti-body screening. An antibody is a protein substance developed by the body's immune system to respond to antigens (a foreign substance or body such as a transplanted organ). Because the antibody may attack the transplanted organ, the antibody screening tests for panel reactive antibody (PRA). White blood cells from the donor and the blood serum of the recipient are mixed to see if there are any antibodies in the recipient that would react with the antigens of the donor (UNOS, 2007).

Other tests performed at this point including a urine test to assess the donors' kidney function, an x-ray and an electrocardiogram (EKG) to screen the donor for heart and lung disease. An arteriogram would also be used to x-ray the blood vessels of the donor kidney.

Another step in becoming a kidney donor is to undergo a psychosocial evaluation. This usually involves psychological testing and an interview to ensure that the donor's decision is voluntary, well-informed, and supported by their social network. The above steps are not followed exactly as prescribed by all transplant centers around the world. They are outlined as the standard protocol by the United Network for Organ Sharing (UNOS), however, and are widely used in transplant centers across the United States.

### **Donor Transplant Outcomes: Mortality and Morbidity**

The most popular procedure for removing a donor's kidney is a laparoscopic nephrectomy (Young, 2007). Laparoscopic live donor nephrectomy was introduced clinically in 1995 with the goal of decreasing financial and logistical impediments to live kidney donation. With assistance from a scope, the surgeon locates, secures and removes

the donor kidney through a small incision in the abdomen (Capelle, 2009). The left kidney is more often transplanted because of its easier access. The laparoscopic procedure, which involves a small incision on one side of the back through which the kidney is removed, has important advantages over a traditional nephrectomy including decreased pain, shortened hospitalization, quicker recuperation from surgery, and an earlier return to work (Ratner, 2003).

After the donor's kidney is removed, the surgical team places the harvested healthy kidney into the recipient's body. Most often the recipient's diseased kidneys are left in place unless there is cancer or another medical condition that would endanger the recipient's health (Young, 2007). Recovery time for both parties most often consists of one week in the hospital.

Segev et al. (2010) investigated the perioperative mortality of living kidney donation using a registry of 80,347 live kidney donors from 1994 through 2009. Surgical mortality from live kidney donation was found to be 3.1 per 10,000 donors and did not change during the course of 15 years. Matas et al. (2003) collected data from 10,828 live donor nephrectomy cases from 243 transplant centers in the United States. Their research provided evidence that perioperative mortality and morbidity are low with live kidney donors. Their study found a mortality rate of 0.03%, which is similar to the annual rate of 0.015% for vehicle fatalities in the United States (Matas et al., 2003; Najarian, 2005). Numerous studies have suggested that the risk of ESRD, hypertension, or other serious health complications following live kidney donation is no greater than the risks of developing these conditions in the general population (Didier et al., 2009; Fehrman-Ekholm et al. 2001; Ibrahim et al. 2009; Matas et al., 2003; Narkun-Burgess et al. 1993;

Ramcharan and Matas, 2002; Ratner, 2003). In addition, the rates of perioperative complications, re-operation, and re-admission to the hospital have been low. Short-term risks include some bleeding during or after the procedure, a small risk of infection, and other potential complications related to any surgical procedure (e.g. a blood clot). Donors also lose time away from work; it can take a few weeks to recover from the surgery and most donors return to work within four to five weeks (Ingelfinger, 2005).

### **Quality of Life with Live Donation versus Cadaveric Donation or Dialysis**

Although this review primarily focuses on the donor, it is helpful to understand the benefits of live donation to the recipients when seeking to understand the motivations individuals have to donate one of their kidneys. The optimal treatment for ESRD, in terms of both quality of life and costs of care, is renal transplantation. Transplantation has been shown to prolong patient survival, improve health status, improve functional mobility, and provide a greater quality of life when compared to renal dialysis (Keown, 2004). Furthermore, in regard to finances, the cost of kidney transplantation is substantially lower than that of dialysis for care that extends beyond one year. The medical benefits of transplantation are most evident in the improved renal functioning experienced by recipients. Dialysis replaces less than 10% of normal renal function, whereas transplantation can return over 50% at least in the first few years. The enhanced freedom and mobility for ESRD patients following transplantation increases their ability to travel and return to work. In contrast, ESRD patients on dialysis must stay near their dialysis center and spend up to 12 hours per week receiving dialysis. Freedom from a lifestyle of trips to the dialysis center, venous needles, dialysis peritoneal catheters and

equipment, are reported to be the most tangible benefits of transplantation (Keown, 2004).

There are also several advantages to living donor transplantation over transplantation using a cadaver donor organ. The use of living donors has been associated with improved patient and kidney graft survival. The UNOS registry reported for 1995 through 1996 that live donor one-year graft and patient survival rates were 91.2% and 97.2% (Leventhal, 2003). These numbers compare favorably with one-year cadaveric donor graft and patient survival rates of 80.6% and 93.3%. After three years post-transplant, graft and patient survival rates for living donor transplants were 83.9% and 94.3% respectively, while cadaveric organs fell to 69% and 87.4% (Leventhal, 2003). More recent data from UNOS indicate the same pattern, as seen in Table 2.1 (“Why a living donation,” 2010).

Table 1. *Kidney Graft Survival Rates One and Five Years Post Donation (U.S transplants from 1997 to 2004)*

<i>Time after donation</i>	<i>From cadaveric donors</i>	<i>From living donors</i>
One year	89%	95%
Three years	78%	88%
Five years	67%	80%

Graft survival for recipients of both living related and living unrelated allografts has been shown to be longer than the survival of cadaveric allografts. Living donor transplantation also helps reduce the long waiting times for cadaveric organs and provides patients with the ability to plan their transplant dates in advance. Other

advantages of live donor transplantation include a decreased incidence of delayed graft function and a shorter period of hospitalization for the recipient (Cecka, 2000).

Furthermore, as the live donor procedure can be scheduled at the recipient's and donor's convenience, this allows for the stabilization of the recipients' medical health before the onset of surgery (Leventhal, 2003).

In summary, living kidney donation has been shown to decrease waiting times to receive a kidney organ, increase graft survival for recipients, and enhance the overall quality of life of patients with ESRD when compared with cadaveric donations or dialysis. These beneficial outcomes have become a strong source of motivation for donors seeking to help family members, friends, and in some instances, even strangers with ESRD.

### **Types of Live Kidney Donation**

The kidney donor may be any healthy person showing a good antigen match to the potential recipient. Prior to the 1990s, the majority of living donors were family members who were genetically related to the recipient. However, unrelated donors, such as spouses and "emotionally related" friends, have become an increasingly popular source of kidney donors (Steiner, 2005). Donors may be genetically related (such as a mother, father, sibling), emotionally related (such as a spouse or significant other), unrelated (such as a friend, church member, neighbor, or coworker), or anonymous (also called a stranger donor or "Good Samaritan" donor).

As a result of the shortage of kidneys available for donation, transplant centers have begun using expanded criteria for evaluating living donors (Ross, 2006). New

methods of matching donors to recipients have also been utilized in an attempt to increase the number of living donors.

**Living paired and cascade exchanges.** The first alternative method for arranging living kidney donation is a kidney paired exchange. In this situation, two donors who are ABO blood type incompatible with their intended recipients partner to complete a compatible exchange. In this type of exchange, Donor 1 is ABO-incompatible with Recipient 1 but is ABO-compatible with Recipient 2, while Donor 2 is ABO-incompatible with Recipient 2 but is ABO-compatible with Recipient 1. Hence, Donor 1 does not give a kidney to his or her intended Recipient 1 but instead to Recipient 2. In turn, Donor 2 gives a kidney to Recipient 1 (Ross, 2006). The cascade exchange between three or more donor-recipient pairs involves the same principles whereby multiple donors are matched with multiple recipients who are not their intended recipients.

**Unbalanced exchanges.** Another alternative method of living donation is the unbalanced exchange. In this scenario, because blood type O donors have the most flexible blood type, these donors are asked to participate in an exchange even though they could donate directly to their intended recipient (Ross, 2006). This can allow another donor-recipient pair to complete a transplant with a patient who is otherwise incompatible. In this scenario, the donor with the O blood type is asked to be "doubly altruistic" because they are not only donating so that the intended (emotionally-related) recipient receives a kidney, but are also allowing a complete stranger to receive a kidney. Some potential donors may be very enthusiastic about having the opportunity of saving two lives instead of just one (Ross, 2006).

**List-paired exchanges.** The list-paired exchange is another variation on living-paired exchanges that involves an exchange between a living donor-recipient pair, a deceased donor, and a candidate on the deceased donor waiting list (Ross, 2006). In this situation, Donor 1 donates a kidney voluntarily to the deceased donor waiting list (Recipient 2) because Donor 1 is not a compatible match with Recipient 1. Following this, Recipient 1 is afforded the highest priority for the subsequent ABO-identical deceased donor organ. Therefore, Donor 1 provides a kidney to a recipient on the waiting list so that Recipient 1 has the ability to receive a transplantation (even though it is a cadaver kidney organ) .

**Nondirected donors.** Another attempt to increase the number of living donors has been the acceptance of the altruistic, or good Samaritan, non-directed living donor. Occasionally, transplant centers in organ procurement organizations receive inquiries from people seeking to donate a kidney to a stranger in need (Matas et al., 2000). The stranger may donate to the list within a specific transplant center or region (Ross, 2006). Some of these donors have launched "donor chains" that have resulted in successful transplantations for multiple recipients (Rivero, 2009).

### **The Motivations of Living Kidney Donors**

#### **Altruism**

Live kidney donation is typically viewed as an altruistic act. Consequently, research related to the characteristics of altruistic behavior may assist in understanding the motives and experiences of living kidney donors. Piliavin and Charng (1990) conducted the most thorough review in the last two decades of the social psychology and

human development literatures regarding altruism. Before the 1980s, many researchers suggested that altruistic behavior could, under close scrutiny, illuminate egoistic motives. Piliavin and Charng found that since that time, theory and data seemed to support the view that true altruism, or acting with the goal of benefiting another, does exist as part of human nature. Multiple definitions of altruism have been offered, but all have emphasized two factors: intentions and the amount of benefit or costs to the actor (Piliavin & Charng, 1990). The definition offered by Bar-Tal (1986) is an example that incorporates these emphases: "altruistic behavior (a) must benefit another person, (b) must be performed voluntarily, (c) must be performed intentionally, (d) the benefit must be the goal by itself, and (e) must be performed without expecting any external reward" (as cited in Piliavin & Charng, 1990, p. 29).

Researchers have found that the decision to donate a kidney to a relative is usually made very readily and often without any sense of actually making a decision. This dynamic is similar to a bystander intervention in which individuals seem to help almost reflexively (Simmons, Klein, & Simmons, 1977). Research has not found a consistent pattern of relationships between personality characteristics and prosocial behavior, though people with high self-regard, sense of competence, internal locus of control, moral development, and low in need for approval are more likely to engage in prosocial behaviors (Piliavin & Charng, 1990). Simmons, Klein, and Simmons found no differences between those who donated a kidney to their relatives and a standardization group on any of the scales of the MMPI, which suggests that family members who donated did not possess personality characteristics that are different from others in the family who did not donate. Research assessing the relationship between attitudinal

measures and charitable giving found that alienation was the only factor that decreased giving (Piliavin & Charng). Further, kidney donors more often endorsed faith in people than non-donors.

Piliavin and Charng (1990) found that esteem-oriented subjects (high in self-efficacy, mastery, self-worth) were more likely to initiate helping behavior in an emergency than safety-oriented subjects (high in need for security, avoidance of anxiety). Piliavin and Charng also found that the “bystander effect” appears to play a role in the chances for an individual to receive a kidney from a sibling in families with multiple siblings. The chances of receiving a kidney from a sibling decreased from 51% when there was only 1 eligible sibling, to 20% when there were 10 or 11 siblings. This may be due to the diffusion of responsibility effect whereby the pressure felt by an individual to rescue a victim is reduced when an individual believes that there are other bystanders available who can offer help. Research has also found that direct requests from persons in need of a kidney may increase the likelihood of a donation. Simmons, Klein, and Simmons (1977) found kidney donors were more likely to have been informed in person of the need for a donor than were non-donors (80% versus 58%). In addition, research on charitable giving, volunteering, and blood donation indicate strongly that a personal request and social pressure were important reasons for participation (Piliavin & Charng, 1990).

### **Donors’ Decision-Making Process**

Russell and Jacob (1993) reviewed the literature on living kidney donor decision making that had been published since 1953. They argued that most of the retrospective

research on organ donors was written to support live organ transplantation and to highlight the benefits of living donation. Therefore, they raised questions about the potential bias in these studies and the potential to underplay donor dissatisfaction. These researchers argued that most kidney transplant investigators clearly considered organ donation to be an altruistic act, and that a positive response from the donors they researched would then be the socially desirable response. They suggested that it is consequently not surprising that a large percentage of donors responded in a positive manner when asked about their live kidney donation. Since their review was published in 1993, however, numerous studies have found that living kidney donors tend to have positive outcomes following transplantation (Binet et al., 1997; Corley et al., 2000; Johnson et al., 1999; Peters et al., 2002; Williams et al., 2009), and no studies have found the opposite.

Simmons, Klein, and Simmons (1977) examined the decision making process used by a sample of 52 donors and potential donors, and found that individuals tend to use one of three different approaches to making these decisions: (1) moral decision making which indicates a seemingly spontaneous choice with no deliberation; (2) deliberation and a conscious choice; and (3) postponement, a situation in which the decision is not made until all other options are ruled out (e.g., the individual is ruled out for medical reasons or becomes the donor after the other potential donors are ruled out). They found that 62% of the sample who decided to donate used the first approach, moral decision making; 23% used the deliberation approach; 4% used the postponement decision approach; and for 17% of the subjects it was unclear whether or not they were demonstrating the deliberation or postponement model of donor decision making. These

findings are consistent with more recent studies that also found that a majority of donor candidates appear to make an immediate decision even before the question to donate was posed by a health professional (Frade et al., 2011; Russell & Jacob, 1993).

Yi (2003) also found three styles of decision making used by living kidney donors though the styles differed somewhat from those found by Simmons, Klein, and Simmons (1977). Using a grounded theory design, Yi interviewed 14 living kidney donors within a week before or after the nephrectomy and found three different types of decision-making within a general category of “wishing to give”: high intensity desire to give which he labeled the *voluntary type*, medium as a *compromising type*, and low intensity as a *passive type*. For the voluntary type, wishing to give their kidney was strong and the course of the decision-making during the execution phase was straightforward (Yi, 2003). The compromising type involved a situation where the desire to give was less intense and the decision-making process more complicated. These individuals started with more passive participation in the compatibility tests, and then developed more voluntary motives as the tests turned out positive (Yi, 2003).

In the passive type described by Yi (2003), the intensity to give was low and the decision-making process was more volatile. These individuals hesitantly took compatibility tests and remained passive throughout the decision-making process and proceeded with more deliberation and ambivalence than the compromising type.

A variety of motivations for living kidney donation have been reported in the research literature. These include parents’ love of their children and desires to help a family member (Franklin & Crombie, 2003; Hilton & Starzomski, 1994; Kim, Yoo, & Kim, 1995), religious convictions, (Farley, 1982; Schumann, 1974), meeting the

expectations of family members, a sense of responsibility and moral duty, and altruism (Diethelm, 1989; Lennerling et al., 2004; Lennerling, Forsberg, & Nyberg, 2003).

The literature indicates that the most influential factor in the decision to donate is a desire to help (Brown et al., 2008; Lennerling et al., 2004; Lennerling, Forsberg, & Nyberg, 2003). For example, Brown et al. (2008) interviewed 12 living kidney donors to assess their motivations for donation and found that the illness experience of a loved one was a strong motivator in their decision to consider donation. Participants indicated that it was very difficult for them to see the recipient undergo the rigors of dialysis and face the accompanying health indications of ESRD, as reflected in the following comment by one of the donors: "I went and saw her on dialysis...and I said, 'Oh my God.' If anybody had a question [about donation] then go and see them put on a machine."

Another concern of the donors was a fear of the impending death or severe disability of the recipient as a result of kidney failure (Brown et al., 2008). The donors also expressed that their philosophy of life had an important influence on their decision to donate. A strong sense of faith and spirituality were evident among the majority of the study's participants as well. For several of the participants, their faith provided a peace and the ability to temper fears about the donation, while for others the decision process involved a much deeper soul-searching process (Brown et al., 2008).

### **Recipients' Reluctance to Ask for a Kidney Donation**

Several studies have found that individuals in need of a kidney donation are frequently reluctant to ask potential donors to consider donating one of their kidneys.

Kranenburg et al. (2007) surveyed 91 patients on the waiting list for a kidney transplant

who did not pursue living kidney donation and found that 78% of the patients on the waiting list were open to accepting an offer from a living donor. The main reason for not seeking out a living kidney donation was a hesitance to discuss the issue with potential donors. Participants indicated that if no one offered to donate one of their kidneys, they interpreted this as a refusal by others to donate a kidney to them.

Waterman, Barrett, and Stanley (2008) surveyed 304 kidney recipients and found that some recipients did not pursue living donation because they did not know how to ask potential donors (Gordon, 2001; Pradel et al., 2003; Waterman et al., 2006). They also found that donors were more likely to initiate the conversation about living donation than were recipients (Waterman, Barrett, & Stanley, 2008). A study by Kranenburg et al. (2009) compared a group of 42 patients who did not find a living donor with a group of 42 patients who did, and found that even though patients recognize the merits of living kidney donation and were willing to accept the offer of a living kidney donor, most participants found it difficult to ask the potential donor directly.

### **The Process of Evaluation and Selection Prior to Donation**

#### **Donor Evaluation and Acceptance**

The evaluation process for determining whether a potential kidney donor is an acceptable candidate for donation is complicated. The donor has to be a healthy individual with suitable cardiac and pulmonary sufficiency. This person should test negative for any form of hepatic disease, and donations are not accepted from those suffering from HIV, cardiovascular disease, terminal infectious diseases, and any form of cancer (Davis, 2004). The screening process is strict and aims to determine whether or

not the donor will remain compliant with the medical regimen that is essential for successful organ transplantation. Other possible contraindications may include any form of mental illness, substance abuse, and immune system depletion.

**Medical requirements.** Not all individuals desiring to donate may be accepted as a donor because of ABO blood type incompatibilities with the recipient. This lack of certainty requires the evaluation to proceed in stages so that expensive imaging techniques are not performed on ABO incompatible donors. The work-up begins with the determination of blood type, blood chemistry profile, complete blood count, coagulation studies, and urinalysis with culture. If the donor is one of multiple siblings who are willing to donate, then HLA typing is performed. This process is done to determine if an HLA identical or one-haplotype match can be determined (Stuart, Abecassis, & Kaufman, 2003).

When the single best donor is identified with the negative cross match, the workup proceeds with a 24-hour collection of urine for detection of protein and creatinine clearance. Next, viral serologies are obtained, chest X-ray, EKG, and, if recommended, a two-dimensional cardiac echocardiogram is performed. Finally, special imaging studies are performed to evaluate the renal vasculature and collecting system. A single imaging technique is utilized which is capable of visualizing both kidneys and the renal arteries, veins and collecting systems. Once these imaging studies are performed, if there is a favorable anatomy and two kidneys are present (some people are born with only one kidney and never realize it), a final cross match is completed. If that cross match is negative, the psychosocial evaluation is favorable, and the requirements of donor

informed consent are satisfied, then a surgery date is scheduled for the transplantation (Stuart, Abecassis, & Kaufman, 2003).

**Psychosocial evaluation.** The use of a psychosocial evaluation has evolved into an important aspect of the overall donor evaluation. As recognized in the Amsterdam forum of 2005 (an international forum that addressed the standard of care for live kidney donors), the use of kidneys from living donors needs to be provided in a manner that minimizes physical, psychological, and social risk to the individual donor and that will not diminish the public trust of the health care community (“A Report of the Amsterdam Forum,” 2005; “The Consensus Statement of the Amsterdam Forum,” 2004; Monaco & Morris, 2005). The psychosocial evaluation of live kidney donors assists transplant teams in minimizing these risks (Adams et al., 2002). It has been suggested that not only does the psychosocial evaluation investigate potential risks, it provides an opportunity for potential donors to manage the psychological experience of the donation decision (Walsh, 2004).

Several researchers have investigated the practices commonly used to achieve the above purposes. Rodrigue et al. (2007) conducted a survey of 132 United States kidney transplant programs to examine how they evaluate and select potential living kidney donors. They found significant variability in evaluation and selection processes utilized by these programs, though they found that most of the programs (70%) would not consider publicly solicited donors, such as those attained through *matching donors.com*. In addition, they found that most programs (75%) require a psychosocial evaluation for all potential living donors, and most programs considered knowledge of financial incentives that had been offered the donors (90%), active substance abuse issues (86%),

and current mental health problems (76%) to be contraindications to allowing a live donation to proceed

Rodrigue et al. (2007) found substantial variability in how other aspects of the evaluation and selection process were handled, however. Consent processes were found to be highly variable across the programs. Donor and recipient consent for the donor evaluation to proceed was presumed in 57% and 76% of programs, respectively. The programs included different issues in their informed consent for the donation to proceed as well. Sixty-five percent of the programs included the issue of alternative donation procedures, while 86% of the programs included a description of evaluation, surgery, and recuperative period in their consent procedures. Forty-three percent of the programs used a "cooling off" period, or a time for donors to process their donation decision before going ahead with the donation.

Kranenberg et al. (2008) reviewed the research describing the various components of the psychosocial evaluation of potential live kidney donors and found notable cohesion regarding the topics included in psychosocial evaluations for live kidney donors. They found the following five topics were commonly included in these evaluations: (1) an evaluation to detect potential clinical psychiatric disorders that may preclude donation, (2) the measurement of psychosocial stability, (3) a determination of whether the donor understands all risks and benefits involved and is able to make an informed decision; (4) the absence of any pressures to donate, and (5) in most cases, the donor's relationship with the recipient and the wider context of the family. Kranenburg et al. (2008) found that the evaluation typically begins as soon as an interested donor contacts the transplant center. During this conversation, the transplant coordinator or nurse initiates a

preliminary evaluation in order to rule out individuals with obvious medical or psychosocial contraindications. Following this interview, candidates viewed as eligible for donation are sent an information packet including donor educational materials. If, after reviewing the materials, the potential donor is still interested in donation, he or she usually contacts the transplant center again to make further arrangements for a full donor evaluation. This evaluation typically consists of an interview and, in the majority of cases, further psychometric testing (Fisher, 2003; Kranenburg et al., 2008; Leo, Smith, & Mori, 2003; Sterner et al., 2006). Fisher (2003), Leo, Smith, and Mori (2003) and Sterner et al. (2006) also described the typical aspects of the psychosocial evaluation within a US transplant center setting. The safety and protection of the living kidney donor is the primary concern of the psychosocial evaluation. Some of the risks of living kidney donation may be psychological and social in nature (Kranenburg et al., 2008; Fisher, 2003; Leo, Smith, & Mori, 2003; Sterner et al., 2006). Depression and anxiety can result from the internal struggle over whether or not to donate a kidney. The fears of undergoing surgery may weigh against the donor's desire to help the recipient in need. Parental donors may have the additional stress of caring for their children while simultaneously attempting to recover from the surgical procedure. Family conflict may arise as certain family members may feel coerced to give an organ or face being criticized if they decline to do so. Furthermore, donors who see their recipients suffering negative outcomes following the transplant may undergo depression and/or traumatic stress reactions (Sterner et al., 2006).

Financial hardship may also result if donors cannot compensate for the missed time from work for both the initial evaluation and recuperation after donation. Some

donors also have to pay for travel expenses, lodging, and other miscellaneous expenses related to their donation. Postoperative complications may also lead to further delay in a patient's return to work. These financial and logistic concerns may contribute to a donor's psychological stress (Fisher, 2003; Leo, Smith, & Mori, 2003; Sterner et al., 2006).

Informed consent is often the first priority for the psychosocial evaluation. In order to make an informed decision, the donor must receive accurate and complete information regarding the medical evaluation process, the surgical operation, the post-surgical recovery, and the potential risks at each stage, and also able to understand the potential outcomes and be mentally and legally competent. It is important that the donor is informed of the recipient's medical status and their other options for treatment (dialysis, cadaveric donation). The donor should also be informed about the potential risks and benefits for the recipient of the other treatment alternatives. If there is concern about a donor's mental competence, then cognitive screening can be used to determine if the individual is able to provide truly informed consent (Fisher, 2003; Leo, Smith, & Mori, 2003; Steiner & Frederici, 2004; Sterner et al., 2006).

Another aspect of the psychosocial evaluation is the donor's motivation for donating. The standard criterion that needs to be satisfied is that the decision to donate a kidney must be made independently. Altruism, duty, responsibility, religious convictions, guilt, social desirability, and attention seeking can all factor into a decision to donate a kidney (Lennerling, Forsberg, & Nyberg, 2003; Yi, 2003). The psychosocial evaluation insures that the decision does not result from coercion or guilt or more subtle pressures that may be exerted by family members or the recipient. Furthermore, the donor may feel societal pressures, cultural expectations, and social desirability that might influence his or

her decision (Russell & Jacob, 1993). In the United States and many other nations, the sale of organs is illegal, but a donor may be influenced by material gifts, employment guarantees, sponsorship for citizenship, or other non-monetary incentives (Sterner et al., 2006).

The donor's relationship to the recipient is another focus of the psychosocial evaluation. It can sometimes be difficult to assess the influence of the donor-recipient relationship upon the donor's decision. For example, a donor may make the decision to donate with the hopes of salvaging or repairing a broken relationship with the recipient or other family members. It has also been suggested that a positive relationship with the recipient can cloud a donor's decision-making and lead to a decision that may not be in the donor's best interest. Part of the purpose of the psychosocial evaluation is to evaluate these relational dynamics and help assist the donor in making an appropriate decision (Fisher, 2003; Leo, Smith, & Mori, 2003; Sterner et al., 2006).

Assessing the donor's mental health is another purpose of the psychosocial evaluation. Psychiatric disorders, emotional stressors, the inability to cope, cognitive limitations, and substance abuse can all have a negative impact on the donor's reaction to the transplant (Fisher, 2003; Leo, Smith, & Mori, 2003; Olbrisch et al., 2001; Sterner et al., 2006). It is also important for the evaluator to assess the potential for mental health problems to appear as a result of the stress of donation.

Evaluating a donor's financial and social support system is another aspect of the psychosocial evaluation. Researchers agree that a donor is unlikely to achieve a successful outcome without the resources to support a physical and emotional recovery (Fisher, 2003; Leo, Smith, & Mori, 2003; and Sterner et al., 2006). Therefore, the

evaluation includes an assessment of a donor's available finances, employment status, and available social support. The donor's social support system needs to be assessed for their ability to assist the donor in the postoperative stage of the kidney donation. In addition to the interview, psychological testing may be used to gain further data regarding the donor's mental health (Kranenburg et al., 2008). Although psychological testing has been utilized at many transplant centers, no standardized battery of tests has been recommended. This is left to the discretion of the evaluators (Kranenburg et al.).

**Psychological contraindications to live kidney donation.** A variety of contraindications to live kidney donation are associated with psychopathology (Kranenburg et al., 2008). The text below provides a listing of psychological contraindications found in publications on this topic (as cited in Kranenburg et al., 2008, p. 182).

Adams et al. (2002):

- A realistic expectation or demand that the transplant will be free from rejection and failure.
- The misperception by the donor that if the transplant is not successful, it is because of personal failure as a donor.
- Monetary compensation.
- A desire for media attention (that could not be supported by the transplant center).
- A response or remedy for a psychological malady, such as severe depression, low self-esteem, or other underlying mental illness.
- A desired selection of the recipient by gender, race or ethnicity.

- A desired involvement in the recipient's life after donation, possibly unwanted by the recipient that could not be supported by the transplant center.

Jacobs et al. (2004):

- An impulsive decision-making process.
- Unrealistic motives to donate (e.g. individual or societal approval, compensation, atonement, redemption, media attention).
- Severe forms of depression, active grief, low self-esteem, or other underlying or untreated mental illness. Candidates are ruled out if psychosocial issues are present that could increase their vulnerability to withstand potential donor-related stresses or that could exacerbate any psychological morbidity.
- Under 21 years of age

Gilbert et al. (2005):

- 'Evidence of significant psychiatric illness'; in that case 'offers are rejected as lacking the mental health necessary for an authentically voluntary offer.'

Dew et al. (2007):

- 'significant past or ongoing psychiatric symptoms or disorders; substance abuse or dependence; limited financial capacity to manage donation (lost wages, travel, job concerns); lack of health insurance; limited capacity to understand donor risks/recipient benefits and alternatives; increased medical risks (e.g. chronic pain conditions); ambivalence about donating,

or unrealistic expectations about the donation experience and potential recipient outcomes; motives reflecting desire for recognition, or a desire to use the donation to develop personal relationships (e.g. desire for publicity, desire for a relationship with an individual or with treatment providers); multiple family stressors/obligations/concerns; subordinate relationship (e.g. employee-employer) or other evidence of coercion; the evidence of, or expectation of, secondary gain (e.g. avoidance of military duty, financial support from recipient); or relationship with family; poor family support for donation.

Transplant centers in the US use generally accepted guidelines in determining contraindications to live kidney donation like those summarized by Kranenburg et al. (2008) in Figure 5 above. At most centers, however, the evaluation of potential donors is done on a case-by-case basis due to the unique constellation of factors involved in each individual case. A standardized decision making process is not realistic given the very large number of factors that can influence a kidney donor's decision to donate.

### **Level of Donor Disclosure: Impression Management and Concealing Information**

A factor that can impair or undermine the ability to evaluate the factors noted above is limited disclosure and transparency by the potential donor during the psychosocial evaluation. Most donors view their donation as making a significant contribution to the quality of life of a family member, friend, or acquaintance, and they consequently often possess a strong desire to donate. By the time the interview occurs, many potential donors have made a definite decision to donate and may say what is

necessary to "pass" the evaluation. This can lead to challenges in obtaining an accurate psychosocial assessment.

Olbrisch et al. (2001) noted that the human tendency to create a favorable impression is natural in most interview situations. However, this potential can become heightened in a psychosocial evaluation. Impression management refers "to the behavioral strategies that people use to create desired social images or identities" (Tetlock & Manstead, 1985, p. 59). Some people are open and offer few defenses in a psychosocial interview, while others try to present an impression that prevents an honest and open exchange of information (Olbrisch et al., 2001).

The research on impression management provides useful background for understanding the potential role played by impression management in the evaluation process for living kidney donation. Tetlock and Manstead (1985) indicate that during the 1960s and 1970s, psychologists focused on intrapsychic explanations involving cognitive or motivational processes of the individual to explain behavior in given situations while focusing less attention on the social context. In the 1980s, impression management research began to suggest that the role of social context and social expectations played an important part in people's behavior (Jones & Pittman, 1982; Schlenker, 1980; Tedeschi, 1981; Tetlock & Manstead, 1985). This research suggested that people are very sensitive to the social significance of their behavior and are motivated to create desired identities in their interpersonal encounters (Tetlock & Manstead, 1985).

In 1990, Leary and Kowalski (1990) conducted a comprehensive review of impression management and provided a two-component model for the construct. They defined impression management as the "process by which individuals attempt to control

the impressions others form of them" (Leary & Kowalski, 1990, p. 34). The model conceptualized impression management as consisting of *two discrete processes*. The first of these processes involved what Leary and Kowalski (1990) termed *impression motivation*, which they viewed as the degree to which people are motivated to control how others see them. They suggested that the motive to engage in impression management is similar to the motivational source of all behavior, primarily to maximize anticipated rewards and to minimize anticipated punishments (Leary, 1995; Leary, 1996).

Leary and Kowalski (1990) divide this first component down into three interrelated yet distinct categories. The first is social and material outcomes. Presenting the right impression can increase the chances that a person will receive desired outcomes and avoid undesired outcomes. Some of these outcomes may be interpersonal, such as approval, relationships, help, and power. Other outcomes may be material, such as a better job and increased salary. The second component is the maintenance of self-esteem. People may engage in impression management to increase their self-esteem by enhancing both the approval of others and their own self-evaluation. The third component is the development of identity. People may also engage in impression management as a way of projecting a certain identity that is desirable to them (Leary & Kowalski, 1990). When individuals are dependent on others for a valued outcome, their motivation increases to use impression management to attain the desired outcome. In the context of living kidney donation, donors may be motivated to use impression management with the evaluator in order to obtain the favorable result of being approved as a donor.

The second discrete process used to characterize impression management, according to Leary and Kowalski (1990), is *impression construction*. Given that a person

may be motivated to create an impression with another, the next question becomes one of deciding precisely the kind of impression one would want to make and choosing how one would go about making the impression.

People use non-verbal as well as verbal communications to project certain impressions. An expansive review of nonverbal behavior and impression management suggests that numerous nonverbal behaviors can contribute to forming a desired favorable impression (DePaulo, 1992; Hill, Gelso, & Mohr, 2000; Kelly, 2000). No matter how people might try, they cannot refrain from behaving nonverbally in their interactions with others. The aforementioned review provides several insights into nonverbal behavior. First, nonverbal behavior is less accessible to the actor than it is to the observer. In other words, people do not see their own facial expressions as others do. The tone of a person's voice also sounds different to him or her than it does to the others based on the audio mechanics of the situation. When people are trying to convey a particular impression of themselves to others, this inability to fully assess their own nonverbal behavior is a limitation. For an evaluator, it is important to watch for discrepancies in a person's nonverbal behavior with the verbal content of their speech. Such discrepancies may indicate a strong motivation to use impression management (DePaulo, 1992).

In the context of living kidney donors, Olbrisch et al. (2001) suggested that impression management needs to be taken into consideration by the kidney transplant evaluators. Outright deception is less common, although it may be used by some potential donors. Recent forensic psychology research indicates that people attempting to deceive will focus on avoiding inconsistencies, the careful release of information, and the

regulation of their nonverbal behavior to appear honest and convincing. In other words, “truth-tellers” provide a more detailed account than “deceivers” (Colwell et al, 2006; Hines et al., 2010). Donors, for example, may attempt to conceal illegal monetary exchanges with the recipient. They may minimize or deny psychiatric contraindications to donation (e.g. psychiatric disorders, substance abuse), as well as pathological motivations for donation. The clinician conducting the psychosocial evaluation needs to distinguish between "genuine and either feigned or strained altruism" in the potential living kidney donor (Olbrisch et al., 2001, p. 46). The detection of these nuances in potential donors is a complex task and requires carefully developed clinical judgment. Olbrisch et al. (2001) recommends that the clinicians develop sophistication in assessing the nuances of impression management and concealment of information, while being careful not to over analyze the genuine altruism demonstrated by many living donors. Other researchers have also suggested that impression management and the concealment of information are important considerations in the evaluation of potential kidney donors (Henderson et al., 2003; Levenson, Valverde, & Olbrisch, 2008; Surman et al., 2005; Tan, Marcos, & Shapiro, 2007).

### **The Experiences of Living Kidney Donors Following Donation**

Kidney donors are monitored in a post anesthesia recovery room following the surgery where their kidney has been removed. A number of indicators are monitored including blood pressure, heart rate, temperature, oxygen levels, alertness, and level of pain. Most donors will leave the operating room with a catheter draining the urinary bladder as well as at least one IV to provide for fluid administration in the early

postoperative period. Patients are not allowed to eat or drink anything until they are completely awake and show no signs of nausea or vomiting (Vincent, Friedman, & Peters, 2008).

After the initial recovery period, the donor is usually moved to a medical-surgical ward. Postoperative pain is managed through patient controlled analgesia (PCA) or epidural methods. All recovering donors are advised to begin walking within 12 to 24 hours following the surgery in order to prevent blood clotting. After the first several days, most kidney donors return rather quickly to the usual basic activities of daily living. In most cases, patients are able to go home within 2 to 4 days following the operation (Vincent, Friedman, & Peters, 2008).

Upon discharge from the hospital, kidney donors are advised not to operate a motor vehicle, power tool, or other machinery due to continued pain medications. They are also instructed not to lift heavy objects greater than 10 pounds for a 3 to 6 week time-period following the surgery to prevent hernias. In the home environment, patients resume all of their normal daily activities over time. A number of patients who have jobs in an office setting, or light duty manual labor, may return to work within 10 to 14 days following the operation. Those with more physically demanding jobs may need to stay home from work for anywhere from 4 to 6 weeks.

### **Physical/Medical Experiences**

Numerous studies have suggested that the risk of ESRD, hypertension, or other serious health complications following live kidney donation is no greater than those found in the general population (Didier et al., 2009; Fehrman-Ekholm et al. 2001;

Ibrahim et al. 2009; Matas et al., 2003; Narkun-Burgess et al. 1993; Ortega & Barash, 2010; Ramcharan & Matas, 2002; Ratner, 2003; Segev, 2010). Matas et al. (2003) collected data from 10,828 live donor nephrectomies from 243 transplant centers in the United States. They found that perioperative mortality and morbidity are low among live kidney donors. They found a 0.03% mortality rate, which is low for a major surgery (Matas et al., 2003; Najarian, 2005).

Ibrahim et al. (2009) recently analyzed a database of kidney transplants performed at the University of Minnesota between 1963 and 2007. They also used the data and death records from the Social Security Administration in order to assess the mortality rate among 3,698 people who donated a kidney during that time span. In addition, the researchers randomly selected 255 of these donors to undergo kidney function tests between 2003 and 2007. Those results were compared with tests done on a group of people who had both kidneys and who matched the donors in race, gender, body weight, and age. Results indicated that the lifespan of kidney donors is similar to that of people who have never donated a kidney (Ibrahim et al., 2009; Seppa, 2009). Results also indicated that ESRD occurred more often in the general population than among living kidney donors (a rate of 180 cases per million persons per year for donors versus 268 per million per year in the general population (Ibrahim et al., 2009). In addition, this research found the prevalence of hypertension and albuminuria in kidney donors to be similar to those in controls who were matched for age, sex, race or ethnic group, and body mass index, even 20 years after donation. Although isolated cases of renal failure have been reported (Kido et al., 2009), there are no large studies that demonstrate evidence of

progressive deterioration of renal function in living kidney donors (Bieniasz et al., 2009; Ibrahim et al., 2009).

Garg et al. (2006) conducted a meta-analysis and meta-regression of 48 studies from 27 countries involving 5,048 donors to assess Glomerular Filtration Rate (GFR) and proteinuria (an excess of serum proteins in the urine that suggests reduced kidney function). The results indicated that donors had a GFR that was slightly lower than controls immediately following donation. However, there was no evidence of an accelerated loss of GFR over that anticipated with normal aging. The proportion of donors who developed clinical proteinuria was slightly higher than expected in the general population. However, the authors recommended that the difference was so small when compared with controls that it should not be interpreted as an identifiable hazard (Garg et al., 2006). Gossman et al. (2005) arrived at similar conclusions in studying the kidney functioning in a sample of 152 donors following donation (years post donation ranged from 1 to 28). Ramcharan and Matas (2002) studied 464 living donors 20-37 years post donation and found that proteinuria and hypertension were similar to the age matched general population.

Williams et al. (2009) analyzed 18 tape-recorded interviews with living kidney donors and found that there were both positive and negative physical reactions by donors following surgery. The majority of the donors said that they did not feel different physically following the donation. In contrast, some of the respondents reported physical discomforts, including pain, nausea, negative drug reactions, and a slower physical recovery than expected. Anderson et al. (2005) reported similar findings and Taylor & McMullen (2008) found pain to be the most significant difficulty following surgery.

Anderson et al. (2007) conducted in-depth interviews of 12 living kidney donors one week after donation and a follow-up interview one year later. All donors reported that they essentially returned to their predonation physical condition within a year of donation. However, over half of the subjects said they experienced medical complaints during the first months post surgery. A reduced physical capacity was the predominant theme related to discharge from the hospital. In addition, donors described a postoperative exhaustion as the feeling of "being knocked out, a feeling of tiredness and a lack of energy" which limited their daily activities (Anderson et al., 2007, p. 705). Several of the donors in the study indicated that this reduced capacity lasted longer than they expected (Anderson et al., 2007).

In addition, the available research found that living kidney donors do not experience short-term health concerns beyond some postsurgical pain and nausea in the 6 to 8 week recovery period. Furthermore, research suggested that the long-term health risks of living kidney donors to develop conditions such as ESRD, hypertension, and diabetes is no greater than that of the general population.

### **Psychological Experiences Following Donation**

**Positive experiences of the donor.** A significant indicator of a positive reaction to the donation experience is the patients' response to the question of whether they would donate again if given the same opportunity with full knowledge of the post-donation outcomes. Research studies indicate that a large majority of living kidney donors would donate again if given the same opportunity (Brown, 2008; Burroughs, Waterman, & Hong, 2003; Fehrman-Ekholm et al., 2000; Isotani et al., 2002; Johnson et al., 1999;

LaPointe Rudow et al., 2005; Shrestha et al., 2008; Wiedebusch et al., 2009; Williams et al., 2009).

Research also found the quality of life of donors to be high and similar to other healthy persons (Clemens et al., 2011). Corley et al. (2000) utilized the Ferraris and Powers Quality of Life (QOL) Index to measure the quality of life from a sample of 72 living kidney donors post donation. They found that living kidney donors reported high satisfaction with their QOL including health, psychological, socioeconomic, and family aspects. Ibrahim et al. (2009) utilized the SF-36 to measure the quality of life of 255 living kidney donors post donation and found that most living kidney donors had quality of life scores that were higher than the population norms and that the prevalence of coexisting conditions was comparable with that found among controls. Other more recent studies found the same pattern of results (Maglakelidze et al., 2011).

O'Driscoll, House, and Holman (2008) measured the quality of life in living kidney donors and found it to be enhanced by the benefit conferred upon the recipient when compared to the short-term inconveniences they experienced post-surgery. A number of other studies found the same pattern of results (Feltrin et al., 2008; Johnson et al. 1999; Maglakelidze et al., 2011; Reimer et al., 2006; Wiedebusch et al., 2009). Other research also found that a sense of satisfaction from seeing the health of the recipient improve as a result of the donation, a positive change in the donor's outlook on life following donation, and improved self-esteem all can result from the experience of donating a kidney (Anderson et al., 2005; Brown et al., 2008; Corley et al., 2000; Sharma & Enoch, 1987; Simmons, Klein, & Simmons, 1977)

Andersen et al. (2007) explored the experiences of 12 living kidney donors one year after donation and found that all participants expressed an overall positive feeling about being a donor. Secondly, donors felt that they had contributed to a better life for another person and were excited by the recovery of the recipient. The donors also expressed a sense of accomplishment and pride connected with their donation (Andersen et al., 2007). In addition, some of the participants also reported that their relationship with the recipient had become more "dynamic and more balanced" as a result of the improvement of the recipient post transplantation (Andersen et al., 2007, p. 704). Other studies corroborate these findings (Brown et al., 2008; Burroughs, Waterman, & Hong, 2003; LaPointe Rudow et al., 2005).

Overall, studies have found the psychological experiences of living kidney donors to be primarily positive. Most of the respondents would donate again if given the same opportunity, demonstrate no deterioration in their quality of life post-donation (some studies found an enhanced quality of life), and experience a variety of psychological benefits from the experience.

**Negative experiences of the donor.** Although research has found that the majority of living kidney donors have positive experiences post donation, the literature revealed some negative psychological experiences. Williams et al. (2009) found several negative emotional experiences among kidney donors. Some donors reported frustration and boredom related to their physical limitations several days and weeks following the surgery. The most prevalent negative psychological experience, however, was sadness and depression after the build-up of the donation experience (Williams et al., 2009). Several other research studies also found depression symptoms to be a negative

psychological experience at some point post-surgery in a minority of donors (Andersen et al., 2007; Jacobs et al., 1998; Johnson et al., 1999; Schweitzer et al., 2003). Lopes et al. (2011) reported that some donors demonstrated higher levels of cognitive anxiety following donation. Brown et al. (2008) also reported that one donor experienced a sense of loss or grief after the donation, saying "When you have a child, you're going to come out of the operating room with something. And now you're going into surgery and you're coming out of there without something" (p. 96).

An unsuccessful transplant outcome due to the death of a recipient or graft failure was the most acute negative psychological experience reported in the literature. In very rare instances, living kidney donors actually have committed suicide as a result (Binet et al., 1997; Johnson et al., 1999; Williams et al., 2009). In most cases, however, the immediate reactions of living donors following an unsuccessful transplant include depression and sorrow, a feeling of emptiness, and a loss of strength (Andersen et al., 2007). These donors did not report any ill feelings toward the medical professionals, denied feelings of guilt or regret about donation, felt satisfied with the psychological support they received from their doctors, and remained confident that they did everything they could to help the recipient through the donation (Andersen et al., 2007). Overall, the literature found negative psychological experiences in a very small minority of donors.

**Importance of donor follow-up.** Kidney transplant centers commonly provide follow-up services to donors including medical care, psychosocial support, and improved donor tracking (Abecassis et al., 2000, Didier et al., 2009; Haljamae, Nyberg, & Sjostom, 2003). Didier et al. (2009) conducted the most comprehensive survey of these practices to date. They contacted all 245 of the programs listed in UNOS, and 226 of the transplant

centers (91%) responded. They found that all of the responding programs provided postoperative care to donors, and 99% of the programs evaluated donors at the center within six weeks following the transplant surgery. They also found, however, that only 20% of the programs attempted to see donors annually for more than two years. The programs reported that donor compliance with postoperative care recommendations (within six weeks of the operation) was more than 90%, but only 26% of the donors (at the 30% of programs that recommended long-term follow-up) were seen two years post-donation (Didier et al., 2009).

UNOS policies recommend the reporting of donor data for up to two years post-surgery; however, these policies do not specify whether the follow-up should occur at the transplant center or at another location (e.g., a primary care physician). Of the programs surveyed, 78% recommended that donor follow-up care be performed by the primary care physician, whereas 22% did not (Didier et al., 2009). The programs that recommended follow-up of living kidney donors by the primary care physician reported that data on blood pressure, kidney function, and psychosocial concerns were rarely received from the patients' primary care physicians, however (Didier et al., 2009). This research also found that mental health evaluations were not usually involved as part of routine donor follow-up and that 32% of the programs report providing such evaluations when concerns arise (10% of the programs plan follow-up evaluations if there are pre-donation mental health risk factors; and 2% limited these evaluations to certain donor types) (Didier et al., 2009).

The programs surveyed reported that the most common barrier to providing donor follow-up is donor inconvenience. Among the programs, 84% cited this as the greatest barrier. Another barrier cited by the programs was financial (involving reimbursement to

care providers and direct and indirect costs to donors). In addition, 63% of the programs indicated that donors often find follow-up unnecessary because they are in good health (Didier et al., 2009).

## **Conclusions from the Literature**

### **Summary of Donor Experiences**

Research on the motivations of living kidney donors has found that altruism is an important motivation for many donors. Factors that have been associated with greater altruistic behavior related to living kidney donation include coming from small families with few siblings, more family involvement in decision making, and initiation by the kidney recipient of the request for the help of the potential living donor.

In addition to altruism, research has found additional varied motives for donating including a parent's love, a desire to help a family member, religious convictions, meeting the expectations of family members, a sense of responsibility and moral duty for altruism, a desire to give, and support from family and community members.

Communication between the recipient and potential donor was also found to be an important factor. Many recipients were found to be hesitant to talk directly with potential donors concerning donation. However, research indicated that having a direct conversation with potential donors increased the chances that they would consider donation.

The process of donor selection and evaluation involves the potential donor undergoing a rigorous physical examination to ensure that the kidney they desire to donate is healthy and that their body is physically able to undergo the donation process.

In addition, the potential donor typically undergoes a psychosocial evaluation which includes an interview with a mental health professional and psychological testing to facilitate a person's informed consent and to evaluate the person's motivations to donate, the nature of their relationship to the recipient, their emotional and behavior health, and financial and social support.

Research suggested that a donor's level of disclosure may be an obstacle to obtaining accurate information from potential donors. Prior to the evaluation, many potential donors have made the decision to donate and have a strong desire to do so. Some may view the psychosocial evaluation as an obstacle to overcome, or a test to be passed, in order to reach their goal. Potential donors may use impression management and conceal information that they worry may be viewed as unfavorable and disqualify them from donating. Several studies identified these dynamics as counterproductive to the evaluation (Henderson et al., 2003; Levenson, Valverde, & Olbrisch, 2008; Olbrisch et al., 2001; Surman et al., 2005; Tan, Marcos, & Shapiro, 2007). However, no empirical research was found that explored this issue in detail. This was found to be a gap in the literature concerning living kidney donation.

The comprehensive meta-analysis by Garg et al. (2006), as well as numerous other studies, found that a majority of donors experience few short-term health concerns beyond pain and nausea post-surgery in the 6 to 8 week recovery period. Furthermore, research suggested that long-term health risks to living kidney donors for developing conditions such as ESRD, hypertension, and diabetes was no greater than that found in the general population (Didier et al., 2009; Fehrman-Ekholm et al. 2001; Ibrahim et al.

2009; Matus et al., 2003; Narkun-Burgess et al. 1993; Ramcharan & Matas, 2002; Ratner, 2003).

The psychological experiences of living kidney donors post donation have been found to be predominantly positive. A large majority of living kidney donors report that they would donate again if given the same opportunity. Quality of life of living kidney donors following donation was also found to be high and similar to other healthy persons. Studies have also found that donors frequently experience numerous positive psychological reactions including personal positive feelings, a sense of satisfaction from seeing the health of the recipient improve as a result of the donation, a positive change in the donor's outlook on life following donation, increased self-esteem, a strong sentiment that they had contributed to a better life for another person, excitement about the physical and emotional recovery of the recipient, a stable or improved relationship with the recipient, a sense that the donation was a very meaningful action, a sense of personal growth, and recognition of their generous act by other people.

Although the majority of donor experiences reported in the research were positive, the literature did reveal some negative psychological experiences. The most prevalent was an experience of sadness and depression related to coming down from the build-up of the donation experience. To a lesser degree, some donors experienced a sense of loss or grief after the donation and psychological stress related to their initial physical recovery. In the event of an unsuccessful transplant outcome because of a recipient death or graft failure, the literature indicated that donors experienced depression and sorrow, a feeling of emptiness, and loss of strength, though these donors also indicated overall satisfaction with their attempt to do their best to help the recipient.

## Conclusions

A large body of literature in social, forensic, and organizational psychology found that people use impression management in a variety of settings to influence the perceptions of others in order to obtain a desired end. There is no empirical research on the use of impression management in the context of kidney donation, however. The present study was undertaken to gain information regarding the prevalence and nature of this possibility among living kidney donors. The mixed-methods design utilized in the present study included a phone survey and a series of focus groups to investigate kidney donors' reports of their use of impression management (and concealment of information) during the psychosocial evaluation. In addition, this study explored the psychological reactions of donors post-donation in order to contribute to the current literature on this topic. Some researchers have been concerned that a lack of full disclosure by potential kidney donors may prevent an accurate psychosocial evaluation and lead to the selection and acceptance of donors who are not truly psychosocially prepared to donate. Even though outcomes for living kidney donors have been shown to be predominately positive, negative experiences do occur. It is possible that some of the donors who had negative psychological experiences used impression management and concealed information about contraindications to donation in order to increase their chances of being approved. Though this concern was raised in the literature, empirical studies to investigate this possibility have not been conducted. Therefore, this study will also investigate the potential relationship between the use of impression management and post-donation experiences.

## CHAPTER III: METHODS

### Mixed-Methods Design

This study utilized a mixed-methods design to investigate the use of impression management and the concealment of information by potential kidney donors during the psychosocial evaluation process, along with donors' psychological reactions post donation. Both quantitative and qualitative methods were used to investigate these questions. A phone survey was administered to a larger sample of participants in the quantitative portion of the study, and focus groups were conducted with a smaller sample of participants to explore the survey questions in more depth in the qualitative portion of the study.

### Participants

#### Phone Survey

The participants in the quantitative portion of this study consisted of living donors who donated at least one year prior but not more than six years prior to data collection at a transplant center in the Midwestern U.S. Both related and unrelated donors were invited to participate in this study, though Good Samaritan donors were not included in the study for the following reasons: (1) they are much fewer in number and a sufficient sample would be very difficult to obtain; and (2) their motives for donation differ significantly from donors who donate to recipients who are known to them.

A total of 144 living kidney donors were contacted to participate in the study.

This included all of the donors served by the transplant center during the period of one to

six years prior to data collection. Of those, 76 agreed to participate in the brief phone interview, resulting in a 53% response rate. Of the 76 donors, 33% had donated 1 to 2 years prior to data collection, 21% 2 to 3 years prior to data collection, 12% 3 to 4 years prior to data collection, 16% 4 to 5 years prior to data collection, and 18% 5 to 6 years prior to data collection). The mean age of the donors was 49.08 years ( $SD = 10.47$ , range = 26-71) and 69% were women. The race of the donors was self-identified as 89% Caucasian, 4% Latino, 4% African-American, and 3% Italian-American. Fifty-four percent of the donors were first degree relatives of the recipients and 46% were unrelated.

### **Focus Groups**

The focus group participants included 21 living kidney donors who, during the phone questionnaire, agreed to participate in the focus group portion of the study. A total of 24 focus group members were originally recruited for the focus groups, but 3 of these canceled on the day of the focus group due to personal scheduling conflicts. To obtain smaller groups, the donors were divided among three focus groups consisting of six, seven, and eight members. The mean age of these donors was 50.47 years ( $SD = 10.47$ , range = 26-71) and 67% were women. The race of these donors was self-identified as 80% Caucasian, 10% Latino, 5% African-American, and 1% French Canadian. Thirty-eight percent of these donors were first degree relatives of the recipients and 62% were unrelated donors.

## Procedures

As part of routine mail follow-up by the kidney transplant center, all donors who had donated at least one year prior but within the previous six years received an invitation to participate in the present study. The letter describing the study along with an informed consent form was followed-up with a phone call to ascertain whether donors were interested in participating in the study. During this conversation, the researcher answered questions and obtained verbal informed consent over the telephone in order to conduct the brief telephone survey. Following the brief phone survey, the participants were asked if they were interested in participating in a focus group to further discuss the issues covered in the phone survey. If they expressed interest, the researcher registered them for one of three focus groups that were scheduled over the following weeks.

### Phone Survey

A brief questionnaire was administered via phone to the participants. The questionnaire consisted of both categorical (e.g., "yes" or "no") questions and interval (Likert scale) questions to gather information about the use of impression management and concealing information by donors in the psychosocial evaluation and whether or not their psychological reactions were mainly positive or negative post donation (see Appendix A for survey questions). This questionnaire took approximately 15 minutes to administer.

## Focus Groups

Three focus groups were also conducted to gather information about the use of impression management and concealing information by donors during the psychosocial evaluation and their psychological reactions post donation. Each group consisted of related and unrelated donors. Dawson, Manderson, and Tallo (1993) define a focus group as “a group discussion that gathers together people from similar backgrounds or experiences to discuss a specific topic of interest to the researcher. The group of participants is guided by a moderator (or group facilitator), who introduces topics for discussion and helps the group to participate in a lively and natural discussion amongst themselves” (p. 6).

After the brief phone survey was completed, the donors were invited to participate in one of three 90-minute focus groups that would discuss the same topics. Krueger and Casey (2009) recommend the target number of participants for each group to be 5-10. Therefore, 6-8 participants were targeted as the number for each group in the present study. The focus groups were videotaped by the primary investigator, and breaks were included to avoid participant fatigue. The primary investigator had significant background in conducting focus groups, analyzing the content of focus groups, and in training focus group facilitators in other research projects. This person also had extensive training in group facilitation.

The focus group protocol consisted of seven open-ended questions designed to stimulate discussion on the participant’s views of their potential use of impression management, deception, and concealing information during the psychosocial evaluation. Additional questions focused on the participant’s psychological reactions post donation

(see Appendix B for the Focus Group Protocol). The participants were also provided with a description of the research project.

At the outset of each focus group, a participant induction was implemented which, following the suggestions of Levers (2006), included the following:

- An overview of the framework for the study
- Specific purposes of the study
- Potential risks to the study participants
- Benefits of the study for participants
- Voluntary status and ability to withdraw at any time
- An explanation of informed consent
- Answering any participant questions about the above issues
- An explanation on how their confidentiality will be maintained
- Confirmation that informed consent has been received by each participant

Following the focus group, a fifteen-minute debriefing session was offered to the participants. The facilitator also offered additional time to debrief if this was wanted. Furthermore, if any of the participants felt that they needed psychotherapy to process emotions triggered by the discussion, this was also offered. None of these additional services were requested by the participants.

### **Data Analysis Procedures**

A *tape-based analysis* of the focus group videotapes and abridged transcripts has been recommended as an effective focus group analysis procedure (Krueger & Casey,

2009; Levers, 2006). Therefore, the video recordings of the three focus groups in the present study were each reviewed and an abridged transcription was completed. To ensure participant anonymity, randomly assigned identification numbers were used to identify participants in the abridged transcripts and data analysis.

The abridged transcripts for each focus group were analyzed by the principal investigator and the content was organized into relevant themes. A comparison of the group member responses with notes from the brief phone interviews was conducted to detect discrepancies between an individual's responses in the initial brief phone interview and the focus group. Dawson, Manderson, and Tallo (1993) advocate for peer reviews or auditors as a means to strengthen the validity of the data analysis. In keeping with this, a psychologist with over 15 years of experience working with living kidney donors acted as the senior auditor of the process and a professional peer assisted in reviewing the data. Dominant themes were identified by the principal investigator, and these findings were reviewed independently by the professional peer who provided feedback on the accuracy of the primary investigator's theme identification. This feedback was then incorporated into a revision of the themes that were identified for each of the three groups. Following this, the senior auditor independently reviewed the themes that were identified for the three groups.

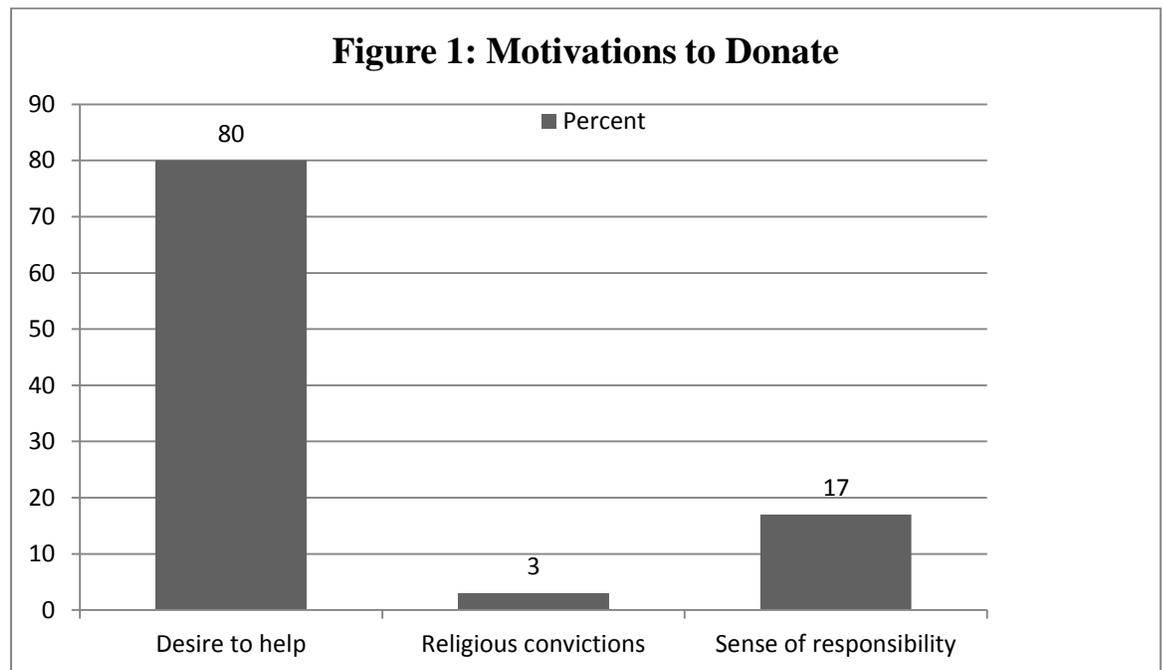
Following the identification of the themes, , the primary investigator performed a cross analysis of the themes for the two types of kidney donors (related and unrelated) to compare similarities and differences in their themes. This cross analysis was reviewed by the professional peer and the feedback was incorporated into a final version. These results were also reviewed by the senior auditor.

## CHAPTER VI: RESULTS

### Phone Survey Results

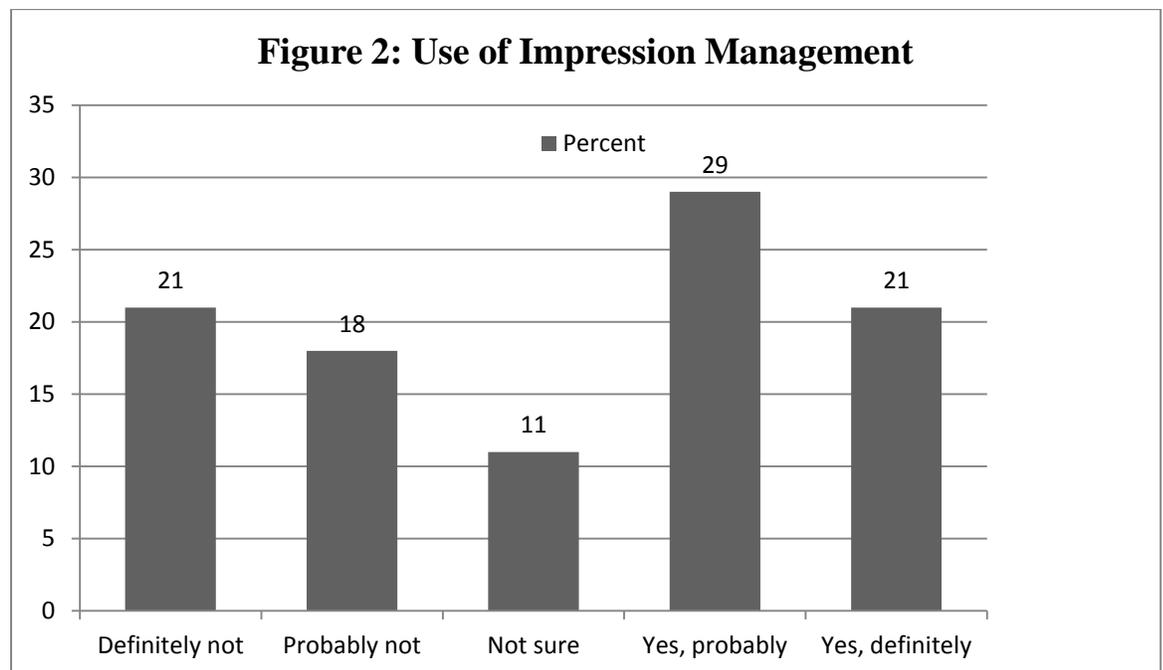
#### Donor Motivations

When asked to identify their primary motivation to donate a kidney, 80% of the respondents indicated that their motivation was "a desire to help," 17% of the respondents indicated "a sense of responsibility or moral duty," and 3% of the respondents indicated "religious convictions" as their primary reason to donate (see Figure 1).



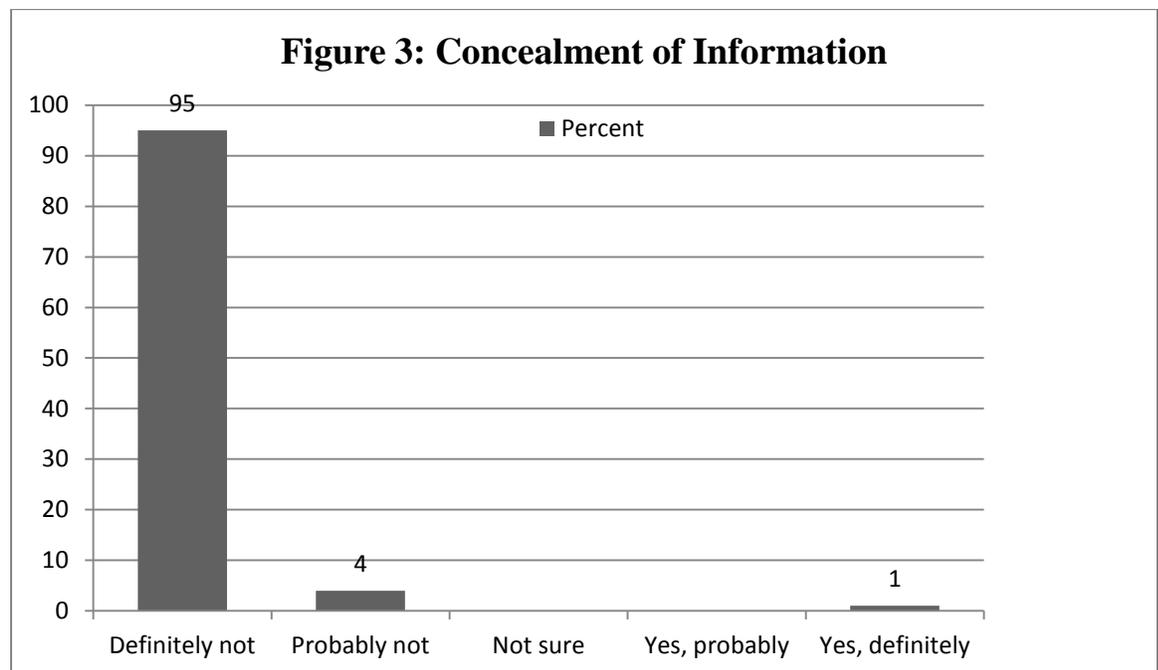
## Impression Management

One half of the donors reported using impression management during the evaluation process for selection as a donor. Specifically, when asked if they tried to create a good impression while being evaluated in order to be accepted as a kidney donor, 21% of the respondents selected "yes, definitely," 29% of the respondents selected "yes, probably," 11% of the respondents selected "I'm not sure," 18% of the respondents selected "probably not," and 21% of the respondents selected "definitely not" (see Figure 2).



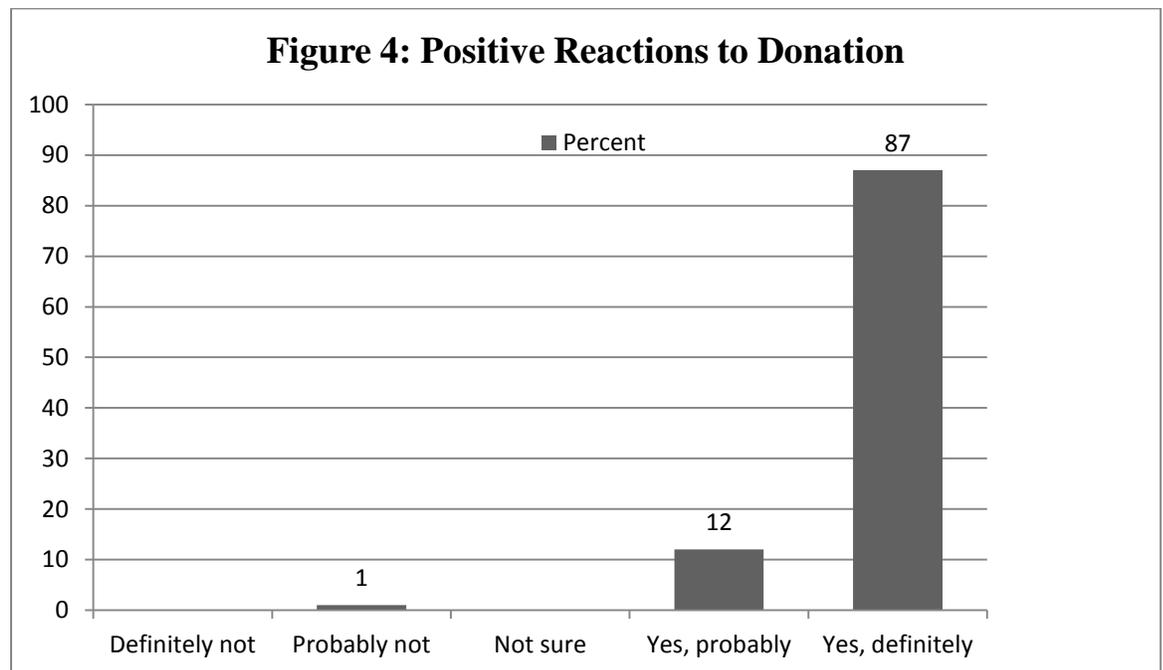
## Concealing Information

Though one half of the donors acknowledged using impression management during the evaluation, a large majority of the respondents denied concealing any information during the evaluation process. Specifically, when asked if they concealed information that they assumed could reduce their chances of being selected as a donor, 95% indicated "definitely not," 4% indicated "probably not," and only 1% (i.e., one respondent) acknowledged that s/he "definitely" concealed information that s/he thought could reduce his/her chances of being selected as a donor (see Figure 3).

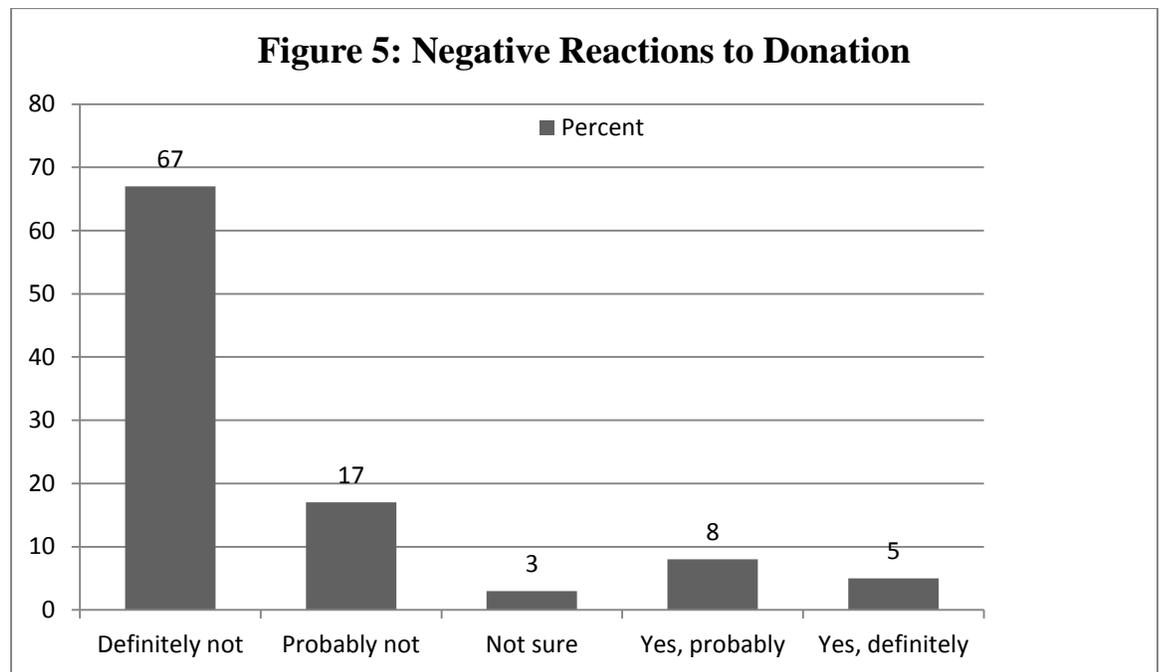


### Donor Psychological/Emotional Reactions Post-Donation

When asked about their reactions to the kidney donation, donors reported many more positive than negative reactions following their donation. Specifically, 87% of the respondents indicated their overall reactions were positive and 12% indicated this was probably the case. Only 1% (one person in the sample) indicated his/her overall psychological/emotional reaction to the donation was not positive. In this situation, the donor reported that the kidney was rejected by the recipient's immune system and the graft failed. This participant indicated that she may have used some impression management during the evaluation interviews, but reported not concealing any information from the treatment team (see Figure 4).

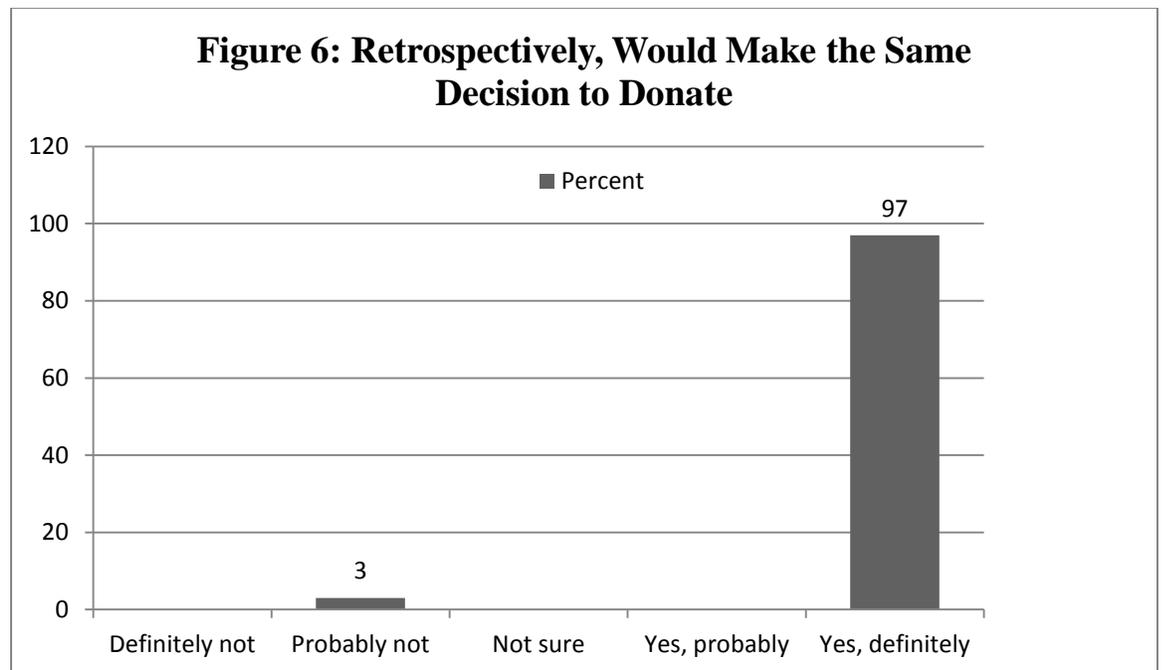


When the donors were asked if they had any negative psychological/emotional experiences following donation, 67% indicated that they "definitely" did not have negative reactions, 17% indicated that they "probably" did not have negative reactions, 3% indicated that they were "not sure," 8% indicated that they "probably" had some negative reactions, and 5% indicated that they "definitely" had some negative reactions to their donation (see Figure 5).



### Retrospectively, Would Donors Make the Same Decision to Donate?

Lastly, donors were asked, in retrospect, if they would have made the same decision to donate their kidney. The responses were almost unanimous that they would as 97% indicated that they "definitely" would have donated and only 3% ( $n = 2$ ) indicated that they would "probably not" have donated. None of the respondents indicated that they "definitely" would not have donated (see Figure 6).



A correlational analysis was performed to explore the relationships between the survey items (see Table 2). Three statistically significant relationships were found. First, there was a positive correlation between having a "positive reaction" following donation and donors indicating that they would make the same decision to donate again,  $r = .48, p = \leq .01$ . Second, and conversely, there was a negative correlation between having a "negative reaction" following donation and donors indicating that they would make the same decision to donate again,  $r = .26, p = \leq .05$ . And, third, a negative correlation was found between having a "positive reaction" following donation and having a "negative reaction" following donation,  $r = .41, p \leq .01$ . The remaining correlations did not reach the level of statistical significance at  $p < .05$ .

**Donor Correlations (Table 2)**

	Good Impression	Information Concealment	Positive Reaction	Negative Reaction	Retrospective Decision
Good Impression		.078	-.034	.188	-.100
Information Concealment			.064	-.039	.031
Positive Reaction				-.413**	.479**
Negative Reaction					-.256*
Retrospective Decision					

\*\* . Correlation is significant at the 0.01 level (1-tailed).

\* . Correlation is significant at the 0.05 level (1-tailed).

## Focus Group Results

Throughout the data analysis process, key phrases or quotes were identified that most accurately represented important themes from the focus group discussions. The following presentation of the results also includes multiple quotations from the donors to convey their specific thoughts and feelings. When multiple quotations are provided, donor statements are delineated by "Donor 1," "Donor 2," "Donor 3," etc. These tags only indicate the order of the particular quotations presented in a given segment and do not identify a particular donor. That is, a quotation tagged as Donor 1 in one section does not necessarily originate from the same donor that is tagged Donor 1 in another section. The statements presented are the verbatim self-reports of the donors and their accuracy is unknown. None of these reports was verified through an examination of medical records or other information.

### Motivations to Donate

A desire to help was the predominant motivation to donate held by a large majority (90%) of the kidney donors in all three focus groups. In many different scenarios, donors identified that they saw the need and possessed a sincere desire to help the person suffering from kidney failure. One of the unrelated donors described it this way:

*This man had PKD [Polycystic Kidney Disease] and was a big beer drinker. At first, people thought that his inflamed kidneys were from drinking too much beer and that he had a beer belly. However, his kidneys swelled to an incredible size. His sister and mother were tested and were not found to be appropriate candidates. When I heard about this situation, I wanted to talk to them and see if they would be open to me being tested. I heard about it and I felt like I could help and make a difference.*

Another donor compared the desire to help her brother by donating a kidney to him as inspired by spirituality and shared the following:

*I know that Jesus died for me and I wanted to make a similar sacrifice in order to help my brother. I wanted others to see that this is what you do when somebody needs your help. I was the only one that turned out to be a match.*

The second most prevalent motivation described by the donors was a sense of duty to do the right thing in donating their kidney. A wife who donated to her husband described a sense of duty that prevailed as she considered her options.

*I went through a variety of emotions in preparing for this decision and came to the conclusion that it was the right thing to do and that I needed to do it.*

Another donor described how a sense of duty does not involve being forced to do anything, but instead involves a strong sense of responsibility that a certain action is the right thing to do in a given situation.

*Yes, it was not that I was guilted into it or anything, it was just the right thing to do. It was a sense of duty.*

Another motivation for donating expressed by a few of the donors was a desire to improve relationships within the extended family.

*I donated over three years ago to my brother. He had a disease which destroyed his kidneys and for me to donate was an easy decision. It was not an easy decision for my husband. He was very skeptical. I did not feel a lot of love in my family and we were not very close because I came from an alcoholic family. For me it was a wonderful opportunity to give to my brother and the family and it was a great opportunity to bring the family together.*

In regard to motivation, several donors from each of the focus groups indicated their decision to donate was clear and easy to make because the choice was obvious. For example, a wife who donated to her husband commented that: “*For me it was a no-brainer.*” Another participant who donated to his sister reflected:

*To me it was simple. It was simple math. My sister had diabetes for some time and I volunteered to be tested. It was a logical decision and there were no emotions involved. To me there was really no decision.*

Donors in all three focus groups emphasized that they possessed a very strong motivation to donate. They reported being emotionally invested and committed to their decision.

*Donor 1: I knew that his friends could not assist. I realized it was the right thing to do and that it would work. I am a person who once I decide something moves forward.*

*Donor 2: When I found out that I was a match, it was a tremendous experience. I have never experienced anything like it in terms of the joy and excitement. I really wanted to do it.*

Donors in all three of the groups also reported difficulty in waiting for their opportunity to donate. Many reported delays (e.g., potential contraindications, the health of the recipient) that prolonged the process and frustration with the subsequent waiting period.

*Donor 1: The medical evaluation was fine. However, the coordinator made a judgment that I was too eager and my husband was on a deadline regarding dialysis. We were a 95% match. I had to wait three months to find out that I was a perfect match and the wait was very traumatic.*

*Donor 2: It was difficult waiting for the amount of time to find out whether or not I would be matched. We were all very anxious and frustrated during this waiting time.*

A large majority of donors reported that they did not view waiting for a cadaver transplant or long-term dialysis as being acceptable options for the potential recipient.

*Donor 1: My husband is a physician's assistant who experienced sudden symptoms of kidney failure. We had been married for one year and he suddenly was admitted to the hospital for kidney failure. It was explained to my husband that he would need to begin dialysis in three months and then we will put you on the cadaver kidney list. I could not handle seeing my husband receive a cadaver kidney. I then volunteered immediately to see what would be involved for me to give my own kidney. I asked myself what would it be like to see him on dialysis and how could I live with myself if I did not offer my kidney.*

*Donor 2: I donated to my oldest brother. There are seven of us siblings and he had symptoms of diabetes and was faced with dialysis three days a week. I could not handle this. I got on the phone after watching him go through a four-hour period of dialysis and said to the other family members that we need to get tested.*

Several donors also reported a feeling that they would be chosen to donate even prior to being accepted as a donor.

*My situation was unique. I donated to my brother-in-law which is odd that we were even a match. There were three brothers of his that were trying to donate, but they did not qualify. Before he was even sick, I took care of a friend who I worked with who needed a kidney and liver donation and saw what she went through in this process. I went through all of this and all of a sudden my brother-in-law's kidney stopped working. He was born with a bad kidney and they could not link it to a disease. My sister called me and said that her husband needed the transplant, and I got off the phone and had the thought that I am the one. I had an odd feeling that this just made sense. It was kind of like a spiritual realization that it was going to be me who donates to him.*

### **Donor's Family Reactions**

A secondary theme that emerged in two of the three focus groups concerned the reactions of the donors' family members to the possibility of donation. One of these involved concerns expressed by the donor's family members about the medical risks of the donation, included the possibility that another family member may need the donor's kidney in a future situation, and pain from the surgery. For example, one donor reported:

*My husband really would've preferred to do it (donate to his sister) himself but he did not qualify. He did not want me to have to go through the pain of the process. He also wanted to make sure I would be available for our kids if they needed a kidney. Unfortunately, it turns out, after the fact, that my daughter does have kidney disease. I don't know how we'll handle this but I am sure when it gets to the point where she may need an intervention or kidney that we will be able to find the help.*

For unrelated donors, the concerns of family members seemed to be even more prevalent, but they did not appear to be strong enough to overcome a strong motivation to donate.

*Donor 1: I talked with my kids and they had some interesting questions. They felt like they would be more supportive if it was someone I knew more intimately. However, I was able to assure them that I would be okay and continue to be able to camp with them, play sports, and other things. These things were very important to my sons.*

*Donor 2: This was a similar dynamic for me as my family members raised the same question. My kids raised the question of whether or not I thought things through. They wondered what would happen if I were to die. My son was concerned that I did not even know this person really well that I was donating to.*

After hearing the above concerns, two other donors in the same focus group reported that they did not ask their children about concerns they may have had regarding the donation.

*Donor 1: That makes me wonder whether or not my kids had some serious misgivings. I really didn't explore this with them.*

*Donor 2: I do want to thank one of the group members for raising the issue of how my kids felt about the donation. That is something that I did not explore with them and I would like to explore this with them at this point.*

Some of the donors in two of the focus groups expressed a concern that few of their family members were willing to be evaluated for potential donation. This was primarily reported by related donors who donated to adult siblings or parents.

*Donor 1: Interestingly, we have two siblings in the medical field and neither one of them volunteered to be tested. That concerned me at first, "what is this telling you", I asked myself, "they know what's going on and they did not volunteer to be tested".*

*Donor 2: We have six kids in my family and one is a medical professional. I was the only one that was willing to be tested.*

## Donor Use of Impression Management During the Evaluation

With regard to the question of whether they used impression management during the evaluation in order to be selected as a donor, the large majority of the donors in all three focus groups acknowledged and described efforts on their part to use some impression management to influence the treatment team in selecting them to donate. For example, some of the donors said they used impression management to convince the treatment team that a known psychological concern, such as past trauma or depression, should not interfere with their ability to donate.

*Donor 1: I definitely used impression management in trying to move the donation process forward. My attempts at impression management were to lay out my concerns in a very frank way to make sure that the treatment team understood how hard I worked on my psychosocial issues in therapy. I did ask my coordinator, if you have a problem with my psychological side, I would be happy to have my therapist meet with you and go through any psychiatric evaluation necessary to demonstrate that I am psychologically stable.*

*Donor 2: I had to meet with a psychologist too. I had the 20 questions and had a bout of depression 10 years ago. They wanted to know from my psychiatrist regarding my medications and treatment for the depression. Of course, the minute that you indicate depression on the application, I knew there would be follow-up on that issue. I wanted to do it, so I was not going to give them an answer that would be the wrong answer and keep me from being able to donate.*

*Donor 3: On the psychological evaluation, I realized I was pretty down because of the loss of my father and the medical issues of my mom. I was concerned how they would take it with some of the emotions that I was experiencing. There was no room to explain it if I indicated I was a little bit depressed... I was afraid they may interpret my feelings as being overly emotional and potentially disqualify me. I wanted them to know that I was not crazy, I might seem like it sometimes, but I am not... In regard to the psychological evaluation, I wasn't sure what to make of some of the questions and what they meant. You really don't know how your responses to these things would be interpreted.*

Several of the donors described their attempts at impression management as being related to their strong motivation to donate their kidney.

Donor 1: *When you are asking about whether or not I thought about how my answers would be interpreted before I answered questions on the evaluation, I definitely did. I thought a lot about the psychology beneath it. I asked myself, "Hmmm, what are they looking for here in this question?" I had a vested interest in donating to my brother-in-law and I know that I did think about my answers and how I came across to the evaluators.*

Donor 2: *Yes, I thought about it. But, it seems like the responses that I gave were both accurate... and most likely the right answer they were looking for.*

Donor 3: *I was taking a psychology course at the time that I went through the selection process. I remember thinking about how to answer the questions and what may be behind them.*

Another segment of donors represented in all three focus groups were aware of physical health issues that might be viewed as a contraindication to donate. Several of these donors described making efforts to convince the treatment team that these physical health concerns should not prevent them from donating.

Donor 1: *I had tried to put my best foot forward in most things. For example, in the stress test I felt my heart was fine but my legs were wearing out or I could've gone forever. I did indicate this to the tester to make sure it was understood as to why I couldn't go further.*

Donor 2: *I had to have some extensive tests because I am an older donor. I had to undergo a heart catheterization in order to be approved as a donor. I worked very hard at working with the treatment team to reach the status of being approved as a donor to my husband. I definitely used impression management in this process.*

In contrast to these various attempts at impression management, 3 out of the 21 participants said they were completely candid in the process and believed they did not use impression management. For example, one donor reported the following:

*They were extremely thorough with me in using multiple tests and an in-depth interview with the psychologist. But, I do not recall trying to figure out what to say in order to create a good impression.*

Taken together, the results from the focus groups indicated that impression management was used by a majority of the donors.

### **Donors Concealing Information During the Evaluation**

The donors were asked if they concealed information during the evaluation process, and 4 of the 21 donors (one or two donors in each of the focus groups) indicated concealing information they thought may prevent them from donating. These donors reported concealing some of their personal concerns regarding donation and the disapproval of their decision by certain family members.

*Donor 1: I concealed some information from the team that I discussed with my husband. My brother-in-law had a heart transplant and ended up not complying with the treatment regimen and ended up dying due to organ failure. I secretly feared my husband might start smoking again and waste the kidney. But, I was not going to tell the treatment team that for fear they may not permit me to donate to him.*

*Donor 2: I think the medical things are more straightforward and easier to lay out on the table. However, some of the psychological things you discuss and handle within your family and don't necessarily share that with the treatment team.*

*Donor 3: The only thing I did not want them to know was that my mother did not approve of my doing this. They asked me if my family was okay with things. I did not admit or volunteer that my mother was upset about me donating.*

*Donor 4: I may have downplayed a little bit the fact that I was concerned she may not take care of my kidney. Yes, I wanted to do it. But, I did conceal the gravity of this concern from the treatment team... I probably didn't make that as big of an issue during the evaluation process for fear they may not like me as a donor.*

No other donors, however, reported that they concealed information that they believed might interfere with their ability to donate.

### **Donors Concern with a Lack of Follow-Up from the Psychology Evaluation**

A theme that arose spontaneously in all three of the focus groups concerned the assessments that were administered as part of the evaluation process. More than half of

the donors (57%) completed test instruments and felt that they were provided no further discussion or follow-up regarding their responses. The following are examples of these concerns:

*Donor 1: For the psychosocial evaluation, I did not speak with anybody. I just filled out a test and purposely filled in a couple items that did not match up just to see if someone on the treatment team would discuss these things with me. That was the one thing that really angered me about the situation... If this was so important, why could I not speak to somebody face-to-face about the psychological side of this thing?*

*Donor 2: I had the same experience and that really bothered me as well. I filled out the questionnaire, and no one discussed this with me. That really angered me.*

*Donor 3: After they drew blood, they handed me the psychological tests and said "here, fill this out." That was it, no communication about this. I noticed a lot of repetition in the questions.*

### **The Positive Psychological/Emotional Reactions of Donors Post Donation**

All of the donors (i.e., all participants in all three of the focus groups) agreed that donating a kidney was a positive psychological and emotional experience. This was the case even for the donors who experienced negative outcomes, such as the recipient's loss of the kidney graft. One of the positive experiences of the donors was the affirmation and esteem they received from family members.

*Donor 1: When people tell me how great everything I did was, it was something I weighed very strongly because I have two sons of my own that may need a kidney someday. I decided to go through the transplant anyhow to help my stepson who needed a kidney now. My (biological) sons came up to me after the donation, looked me in the eye, and told me how proud of me they were. Even though the graft was rejected by my stepson, my other son's feelings of pride were a tremendous positive experience for me.*

*Donor 2: It was an overwhelming experience because everyone was so supportive and I felt positive all the way through because we had people praying for us all over the world. We had overwhelming support from our children... Many other extended family members were with them during this time. When I woke up from*

*surgery, it was like having a line up in my room of people there to support me. "What are you all doing here" I responded as I was amazed by how much support I had in the room.*

Another benefit reported by the donors was increased self-esteem from donating their kidney.

*I was sexually abused when I was young and it was a long road to recovery for me. I never did feel that I was a great person. The abuse made me feel so badly about myself. All that sadness never quite left me and my self-esteem was not very high. I will never forget the second day of the surgery as I was lying flat on my back in the hospital and I'm looking at the ceiling and all of a sudden I got this big smile on my face because it was my first personal moment with myself ever and I said to myself "my God, you did this without any strings, without any conditions, I think I like you." I started liking myself at that point. All of a sudden, I really liked the kind of person I was becoming. It was a really positive experience and I've had a smile on my face ever since.*

Similarly, other donors characterized the most positive benefit as an enhanced sense of meaning and purpose in life.

*Donor 1: It was a more internal thought process for me. It is no big deal and everybody should do this. I had people make comments at work about how great it was that I did this. I just started thinking about my life and this process caused me to think about the question, "what have I done in my life when I die that is significant?" You start thinking about all the things you've done in your life and what you learned and how to step it up and engage in a positive experience like this. I was not as concerned with showing everybody what I did. It was more of an internal experience. It was one of the best things I have done. It was similar to giving birth to my children.*

*Donor 2: I would do it again because the overall experience was positive. I think it taught my children something. I think it was a reality check for my spouse and a reality check for me on life, living, and the meaning of life.*

Several of the donors reported that donation improved their relationships with extended family members. One of the donors believed that her donation united her family and reported:

*In my situation, it was wonderful to see how this united my family. It is nothing like it was before. It is so great. It is a blessing every day and I'm so thankful for how their relationships have changed. Our kids did not even know one another*

*before the donation. It changed everything. My sister-in-law knowingly hated my husband before the transplant. It has changed everything.*

Another donor added:

*It is the same for me in regard to family relationships. My brothers were not very close and we never said I love you in my family. Now we appreciate one another more. This is something I did not expect of the situation. Christmas is so much more fun. Even the younger brother that was upset that I was the one to donate is now really close to me and expresses appreciation for me often.*

The most prevalent positive psychological/emotional experience reported by the donors was a sense of satisfaction in seeing the recipient resume a healthy and functional life. Many of them identified this as the most beneficial experience in donating.

*Donor 1: Seeing my recipient take his family to the park following the surgery and seeing him in good health was an excellent experience. He could not do this before because he was in pain and had no energy. Before the surgery, the experience was a roller coaster for them as a family because they had a premature baby. Just to see him be able to be a father and participate fully in activities was incredibly rewarding for me.*

*Donor 2: Emotionally I was very pleased. My brother improved so fantastically. From day to day his condition was so incredibly better.*

### **The Negative Psychological/Emotional Reactions of Donors Post Donation**

Although the psychological/emotional reactions of the donors in all three of the focus groups were predominantly positive, there were some negative reactions. Two of the unrelated donors experienced situations in which the graft kidney they donated was lost. One of the donors described their situation as follows:

*After the first day, we realized that we were losing the kidney. My stepson's body rejected the kidney. This was not supposed to happen. I was a mess and very distraught. Our entire family went through a very trying time because of this. This seemed to be a 1 in a 1,000 chance that this would not work. We went through a lot of difficult emotions during this time. However, the story has a good ending because my stepson received a perfect match one year later and is doing well.*

Some of the donors reported negative emotions during periods of temporary rejection of the graft by the recipient's body. Some of these donors even reported experiencing feelings of guilt during these situations.

*I think the rejection piece really bothered me. He was doing very well and then went through a short period of rejection. I knew it was not my fault but I still felt emotionally anxious and semi-responsible. For instance, one of these instances happened during his son's birthday and I felt really bad. But things are going well now.*

Several of the donors also expressed negative emotional reactions related to noncompliance by the recipient in caring for the kidney. For example, one donor described the disappointment in seeing her husband continue smoking following the transplant,

*Just recently things have not gone that well for my husband even though the transplant was initially successful. The reason why is my husband has continued to smoke. They did have reservations toward the end of the evaluation process about doing the transplant because of the smoking. However, they did proceed. He is starting to have a few problems with the kidney.*

She added,

*This is a hard issue for me with my husband because we're so close. It is hard to see the recipient not take care of themselves the way you would like them to. In my case, it is very frustrating for me that we have come to this place and worked so hard and my husband continues to smoke and put the kidney in jeopardy.*

### **Donor Reactions to the Transplant Team**

During the course of the focus groups, several participants voluntarily offered opinions of the transplant team. Three focus group members shared appreciation of how the treatment team handled the donation for themselves and the recipient. One donor offered the following:

*I felt like I was royalty during the process, though, and enjoyed how I was treated in terms of the treatment team considering my needs as well as the recipient.*

Several other donors also shared their appreciation of their transplant coordinator and the surgeons. For example, one of the donors felt the coordinator was thorough in eliminating any potential pressure to donate.

*The coordinator that I dealt with was great. Everything was very verbal and personal and they were very thorough to make sure I did not feel any pressure to donate. Even on the morning of, they checked with me again to make sure I did not feel pressure.*

In contrast, there were six donors who indicated some disappointment regarding the care provided by the team. These donors reported desiring more compassionate care from the treatment team.

*I felt like I was rather ignored and there was no communication afterwards by the treatment team with me or a sense that they cared about my follow-up.*

Another donor described regret that he did not see the surgeon before or after surgery,

*In regard to the surgeon, I only saw the surgeon once prior to surgery. Unless I was drugged and I do not remember him coming into the operating room, I did not have the chance to see him or speak to him before the surgery or afterward. I felt like this was a disservice to me. You might do this every day but this is a once-in-a-lifetime thing for me. I deserve for you to come and see me before you cut me open. That was the only negative I took away from the experience. Everyone else was wonderful.*

### **Donor Experiences with Follow-Up Post Donation**

Another theme (reported in all three of the focus groups) was disappointment in the level of follow-up after donation—80% of the donors reported feeling this disappointment. The following statements illustrate their concerns:

Donor 1: *Did anyone feel like after the transplant you had one checkup appointment a month after and that was it.*

Donor 2: *I have to say I was kind of disappointed in the follow-up. I was told to come back in six months for follow-up and they did a very cursory physical. I left and no one ever recommended I should monitor my creatinine and as it turns out one of my (primary care) physicians recommended I get it checked. It turned out to be high. Even now I have questions and would love it if someone would take time to talk to me about these issues.*

Donor 3: *I think I just wish I knew that there was a contact. A little more care for those that are the donor would've helped I think over the last several years.*

Donor 4: *This really made me think about how important good living kidney donor care afterwards and follow-up is. If we want to encourage people to do things like this, there should be better aftercare. I had a couple of follow-ups. But, they said for me to see your primary, but I do not have a primary because I do not have insurance. They would say, well, when you get one then you can see them. They seemed a little dismissive in phone calls when I had medical questions they would say I don't think that has anything to do with the kidney. I am just hoping the message will get out that there needs to be good quality aftercare for living kidney donors. I think these things are valuable. (Many others nodded their heads in agreement).*

### **Retrospectively, Would Donors Make the Same Decision to Donate**

When asked if they would make the same decision to donate, all of the participants said they would do the same thing without hesitation, including the donors who experienced some negative reactions. For example, donors reported:

Donor 1: *I would still die in a heartbeat for something I believed in. And, I believed in this. I look at soldiers doing what they're doing and I feel what I did was unheroic in comparison. It was a no-brainer.*

Donor 2: *There was no question for me either to do it. The need was there and I asked myself what I can do. If I was faced with this situation again, I would not question it.*

Another described kidney donation in a spiritual context.

*Even though things did not go perfectly for me, I do not regret donating my kidney. I feel like there is a parallel here with the sacrifice Christ made for us for those of us that have a Christian viewpoint.*

Another responded as follows:

*I am not a Christian, but I do agree with you on the symbolism and a parallel between donating a kidney and Christ's sacrifice.*

### **Donors Desire Support from Fellow Donors and Want to Share Their Experience**

Additional themes that arose in all three of the groups were a desire for support from fellow donors (both before and after donation) and a desire to share their experiences with others. Approximately one-half ( $n = 10$ ) of the donors commented on the importance of support from fellow donors.

*Donor 1: I didn't go through the same waiting game as those that were donating to spouses and the anxiety. However, it would've been really nice to have a network of other donors I could talk to who were going through the same thing.*

*Donor 2: Yes, I would like to have had an opportunity to meet in groups like this. I would like to have been able to talk to somebody that had already donated. This would've helped me with my fears.*

*Donor 3: I had a couple of those connections before I donated who helped me through the process. One is a family member and one was a friend. It was incredibly nice to have the opportunity to talk with both of them. That got me through a couple of worrisome nights.*

Several of the donors also described their desire to share their donation experience with other people.

*Donor 1: I gave a talk at my church regarding this whole thing after I donated. The National Kidney Foundation gave me all kinds of helpful information to distribute.*

*Donor 2: I spoke at my church to all three services. My stepson also talked about his experiences with the transplant. It was a very moving and powerful experience.*

*Donor 3: I was one of the first ones to volunteer. I definitely wanted to have an opportunity to tell my story.*

### **Consistency of Donor Responses on the Phone Survey Versus Focus Groups**

The responses that participants gave in the focus groups were compared with their telephone survey responses to identify any discrepancies that might suggest that their responses were affected by hearing about the experiences of other donors. Donor responses to the phone surveys were found to be consistent with their responses in the focus group. In the large majority of cases, there was no evidence that group dynamics changed the opinions or reports of the individual participants.

There were two exceptions to this general finding, however. In one case, a donor indicated in the phone survey that he would “probably not” donate again because of multiple medical complications resulting from the surgery. In the focus group, however, he indicated that he would do the same thing again without question. In the other case, a donor indicated on the brief phone questionnaire that she experienced no negative psychological or emotional reactions from the donation. In the focus group, however, she revealed a negative emotional reaction related to the lack of a desired relationship with the recipient.

### **Comparing Responses of Biologically Related Versus Biologically Unrelated Donors**

A comparison of the responses of the biologically related versus unrelated donors in the focus groups demonstrated some noteworthy differences. Thirty-eight percent of the donors in the focus groups were first degree relatives of the recipients and 62% were biologically unrelated donors. The families of some of the unrelated donors expressed more concern about the donation when it was to someone the donor did not know extremely well (e.g., a long-term friend at work). This unrelated group of donors reported

that they had to address and discuss more of these concerns with their family members than the related donors.

Two of the unrelated donors who did not have a close relationship with the recipient experienced disappointment in their relationship with the recipient following donation. These unrelated donors had hoped to develop an improved relationship after the transplant; however, their relationship actually deteriorated and the donor received little contact from the recipient. In contrast, a large majority of the related donors (and unrelated donors who donated to in-laws) experienced improved relationships with the recipient and the extended family as a whole.

## CHAPTER V: DISCUSSION

### Impression Management and Concealing Information

The first question explored in this study concerned the extent and ways that living kidney donors use impression management and the concealing of information during the psychosocial evaluation for determining acceptability for a kidney donation. The reported use of impression management by the study sample was high. One half of the participants in the phone survey reported using impression management during the evaluation process for selection as a donor. In addition, a large majority of the donors in all three focus groups acknowledged and described efforts on their part to use some impression management to influence the treatment team in selecting them to donate.

This study found that the use of impression management was often related to a strong motivation to donate one's kidney. It appeared that many of the donors in the present study minimized known psychological concerns (e.g., past trauma, depression) in order to increase their chances of being accepted as a donor. In the focus groups, several donors acknowledged evaluating questions on psychological measures and during interviews in order to provide answers that they believed would increase their chances of being selected to donate. Other donors sought to overcompensate for and minimize the concerns the treatment team had regarding known physical health issues that may have prevented them from donating. This is the first study to empirically explore the prevalence of the use of impression management by individuals undergoing evaluations to donate one of their kidneys, but these findings suggest that impression management is used relatively frequently by living kidney donors. These data help confirm the intuitions

of previous researchers who believed that impression management may be an important consideration in the evaluation of living kidney donors (Henderson et al., 2003; Levenson, Valverde, & Olbrisch, 2008; Surman et al., 2005; Tan, Marcos, & Shapiro, 2007).

The present study also found evidence that supports the suspicion that kidney donors occasionally conceal information during the evaluation process (Henderson et al., 2003; Levenson, Valverde, & Olbrisch, 2008; Surman et al., 2005; Tan, Marcos, & Shapiro, 2007). The prevalence of concealing information, however, was found to be low. The phone survey found that only 1% of donors reported concealing information in their evaluations, and only 14% of donors in the focus groups acknowledged concealing any information during the evaluation. These donors primarily concealed fears regarding donation or the disapproval of their family members. A correlational analysis found no statistically significant relationship between donor concealment of information and any other factors. Further, no evidence was found suggesting that donors concealed information regarding alcohol or drug problems or significant psychological problems, financial difficulties, or health problems. These results suggest that the living kidney donors in the present study infrequently concealed information and that, when it occurred, the concealed information involved issues that were relatively less significant in the donor selection process. This study uncovered no information suggesting that the donors concealed issues related to factors that would be critical in determining their acceptability as a living kidney donor.

The donor experiences reported by the participants in this study are also consistent with the two component model of impression management presented by Leary

and Kowalski (1990). The large majority of the donors acknowledged a strong motivation to be selected as a donor, which is consistent with Leary and Kowalski's first component of *impression motivation*. These donors reported feeling strongly that they wanted to improve the health of a family member, spouse, or friend in need of a kidney. Second, at least 50% of the donors also engaged in the process of *impression construction* by saying what they thought the evaluators wanted to hear and downplaying health conditions or psychological feelings which they thought would be undesirable to the evaluators.

It is also noteworthy that the reported use of impression management was not statistically significantly correlated with the donor's reported reactions post-donation, suggesting that living kidney donors who utilize impression management do not tend to have negative post-donation reactions to the experience. (There was a trend in this direction between reporting the use of impression management and reporting a negative post donation experience, but the correlation was not statistically significant,  $r = .19, p = .052$ ). However, some of the donors in this study who used impression management during the kidney donation evaluation may have used the same strategy in responding to the research team conducting the present study. This dynamic could have resulted in the underreporting of both the use of impression management during the evaluation and having negative reactions to the donation. To the extent that the donors in the present study accurately reported their behavior and experiences, however, the present findings tend not to substantiate the concern expressed by numerous researchers that impression management by potential kidney donors can result in less reliable evaluations and potential difficulties with adjustment post-donation (Henderson et al., 2003; Levenson, Valverde, & Olbrisch, 2008; Surman et al., 2005; Tan, Marcos, & Shapiro, 2007).

### Psychological Reactions of Living Donors Post Donation

The second question investigated in this study concerned living kidney donors' psychological reactions following the donation. In this study, 99% of the phone survey participants indicated that their overall psychological reactions to their donation were positive. The results of the focus groups paralleled this finding as participants unanimously endorsed positive psychological experiences after their donation. The findings are consistent with the results of other research indicating that donors have primarily positive psychological reactions after a kidney donation (Anderson et al., 2007; Brown et al., 2008; Corey et al., 2000; LaPointe Rudow et al., 2005; Simmons, Klein, & Simmons, 1977; Williams et al., 2009). In this study, these positive benefits included affirmation and positive esteem received from family members, increased self-esteem, enhanced sense of meaning in life, and enhanced family relations. The most prevalent positive psychological experience reported by the donors in the focus groups in this study was a sense of satisfaction in seeing the health of the kidney recipient improve as a result of the donation, which is also consistent with the findings of previous research (Brown et al., 2008; Williams et al., 2009)

The kidney donors in the present study also reported some negative psychological reactions to donation. In the phone survey, 13% of the donors reported negative reactions, while 9% of the focus groups participants reported experiencing depression, sorrow, and intense psychological distress that resulted from the failure of the kidney graft following their donation. Their reactions were similar to donors who reported graft failure in previous research (Anderson et al., 2007). Other negative reactions reported in the focus group portion of the current study included difficult emotions during periods of

temporary graft rejection endured by the recipient (10%, or 2 of 21 of the donors), a sense of disappointment in the focus moving from themselves to the recipient following surgery (10% of donors), and disappointment with the noncompliance of the recipient in caring for the kidney (5% of donors).

Nearly all of the phone survey participants (97%) in the present study and all of the focus group participants indicated that they would make the same decision to donate their kidney as they look back retrospectively at their whole experience. This is consistent with the results of several previous studies (Brown, 2000; Burroughs, Waterman, & Hong, 2003; Fehrman-Ekholm et al., 2000; Isotani et al., 2002; Johnson et al., 1999; LaPointe Rudow et al., 2005; Shrestha et al., 2008; Wiedebusch et al., 2009; Williams et al., 2009). In the phone survey, a positive relationship was found between reporting positive reactions post-donation and donors reporting that they would make the same decision again ( $r = .479$ ). In contrast, however, even those donors in the focus groups who experienced some negative reactions (e.g., due to graft failure) reported that they would make the same decision again without hesitation.

### **Additional Findings**

The discussions in the focus groups in the present study revealed several additional themes that are relevant to the kidney transplant process. A majority of these donors indicated some disappointment with the treatment team, particularly in terms of desiring more attention and concern. In contrast, the rest of the donors who reported more positive experiences with the transplant treatment team generally identified frequent and supportive communication from the team coordinator as well as consistent attention and

care throughout the process. It is not possible to evaluate whether a large group of donors actually received significantly less attention and care throughout the donation process—this possibility may be less likely because it was largely the same transplant team that provided the clinical care for the whole study sample (there was relatively little turnover in the transplant center staff during this time). Another possibility is that those donors with a less positive outlook and personality may have interpreted the adequacy of their care less positively, even though it was similar to the care received by those who were satisfied with the care they received.

A large majority of the donors in the focus groups also expressed a desire to have more follow-up after donation. Many researchers have recommended improving the long-term medical and psychosocial follow-up support provided to living kidney donors post donation (Abescasses et al., 2000; Didier et al., 2009; Haljamae, Nyberg, & Sjostom, 2003). Some follow-up is common among US transplant programs, but only a minority of the US transplant programs surveyed by Didier et al. (2009) evaluated donors after three months, and only 20% of programs attempted to evaluate donors at least annually after two years.

### **Implications for Clinical Practice**

In the present study, one-half of the kidney donors reported using impression management to increase their chances of being selected as a donor. In addition, a small number of donors also acknowledged concealing information from the treatment team. Though the information that was reported as having been concealed was of relatively lower importance than other information that is critical in a kidney donor evaluation,

nonetheless a minority in the study sample reported intentionally concealing information that was requested. Therefore, transplant centers should remain alert to the possibility that these factors may be affecting the information received during living kidney donor evaluations.

To help address this issue, transplant centers could consider using assessments designed to detect faking or misrepresentation if they suspect high levels of impression management or the concealing of information. Developing strong rapport with potential donors can also help staff evaluate the nuances of a donor's psychological presentation.

Providing opportunities for donors to receive support from past donors may also help donors feel supported, understood, and more comfortable with the transplant process. Many donors who participated in the focus groups in the present study reported that they would have welcomed this type of support both before and after their donation. Transplant centers might provide this support in the form of a support group or by arranging mentoring relationships with previous donors.

The reports of the donors in the present study also suggest that additional medical and psychosocial follow-up post donation would have been beneficial for improving their overall donation experience. With regard to medical follow-up in general, 78% of surveyed US kidney transplant programs recommended that medical follow-up care be performed by the primary care physician (Didier et al., 2009). However, that same study found that the primary care physician follow-up of living donors rarely resulted in obtaining data on blood pressure, kidney function, and other important medical indicators. If follow-up care is to be provided by primary care physicians, improved

communication between transplant centers and primary care physicians may result in improved monitoring of the outcomes and adjustment of kidney donors.

The current findings also suggest that the most important follow-up desired by the donors would involve knowing that transplant providers are concerned about their medical and psychosocial outcomes and any potential concerns they might have. In many cases, demonstrating this concern might be accomplished relatively easily through phone calls or letters to advise donors that the transplant team wants to inquire about how they are doing and whether they need further care.

### **Study Limitations**

The present study recruited kidney donors from only one transplant center, and no attempt was made to evaluate whether the experiences of these donors was similar to those who donated through other kidney donation programs. The primary limitation of the focus group portion of the present study was the small sample size ( $n=21$ ), though the phone survey portion of this study used a larger sample of donors ( $n=76$ ) to help offset this disadvantage. The response rate for the phone survey was high and the sample was drawn from the whole population of donors from a relatively large kidney transplant center. Nonetheless, the study results cannot be generalized to the wider population of living kidney donors.

### **Directions for Future Research**

The findings of the present study regarding the relatively common use of impression management and the uncommon use of information concealment during the

evaluation process for kidney transplantation should be replicated with a larger sample of donors from multiple transplant centers. More information about these factors may help improve the reliability and accuracy of donor evaluations. A better understanding of the potential benefits of more follow-up for kidney donors may also help improve the overall experience of live kidney donors. Further, the relationship of these factors to donor outcomes also could be explored in more detail to help identify improvements that can be made to clinical practice in the field. Given the major benefits of live kidney donation for improving the quality of life for those diagnosed with ESRD, research that leads to improved experiences for living kidney donors is an important undertaking.

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## Appendix A: Survey

**Survey Questions (for both related and unrelated donor groups)**

DO NOT ASK THE FIRST FOUR QUESTIONS  
IF THE INFORMATION IS AVAILABLE FROM THE PATIENT RECORD

1. What is your age? \_\_\_\_\_ yrs old
2. What is your gender? Male Female
3. How long ago was the donation?
  - a. Less than one year ago
  - b. 1 to 2 years ago
  - c. 2 to 3 years ago
  - d. 3 to 4 years ago
  - e. 4 to 5 years ago
4. Which of the two types of donors are you?
  - a. Related (a blood relative)
  - b. Unrelated (via know the donor but they are not a blood relative)

Open-ended rapport building questions: Ask the donor how they are feeling and how their recovery went following donation and establish rapport before moving to other questions.

5. Research suggests people have a variety of motivations to donate a kidney. Some of those reasons reported by donors are listed below. In your case, what was your primary motivation to donate a kidney?
  - a. A desire to help
  - b. Religious convictions
  - c. A sense of responsibility or moral duty
  - d. To meet the expectations of family members
  - e. Other: \_\_\_\_\_
6. Research suggests that some donors try to create a good impression during the evaluation interviews so that they will be accepted as a donor. Would you say that you tried to create a good impression during your evaluation so that you would be accepted as a donor?
  - a. Definitely not
  - b. Probably not
  - c. I'm not sure

- d. Yes, probably
- e. Yes, I definitely did

7. Research also suggests that some donors may conceal information that they assume may reduce their chances of being accepted as a donor (including, but not limited to, alcohol or drug problems, psychological problems, financial difficulties, or health problems)? Do you feel that you concealed any information during your evaluation interviews?

- a. Definitely not
- b. Probably not
- c. I'm not sure
- d. Yes, probably
- e. Yes, I definitely did

8. What have been your psychological/emotional reactions after donating your kidney? Overall, would you say it was a positive experience?

- a. Definitely not
- b. Probably not
- c. I'm not sure
- d. Yes, probably
- e. Yes, I definitely did

9. Did you have any negative psychological/emotional experiences?

- a. Definitely not
- b. Probably not
- c. I'm not sure
- d. Yes, probably
- e. Yes, I definitely did

10. In retrospect, would you still have made the same decision to donate your kidney.

- a. Definitely not
- b. Probably not
- c. I'm not sure
- d. Yes, probably
- e. Yes, I definitely would

Appendix B: Focus Group Questions

**Focus Group Questions (for both related and unrelated donor groups)**

1. Describe your primary motivation to donate a kidney? How did your motivation to donate affect how you interacted with those evaluating/deciding whether or not you were able to be a kidney donor?
2. How would you describe any attempts that you may have made to impress the evaluator, when being considered as a donor, that you were a suitable (if not ideal) donor? How did evaluators respond to these attempts?
3. How would you describe any concerns that you thought might keep you from being a donor (e.g. alcohol or drug problems, psychological problems, financial difficulties, or health problems)? How did you deal with these concerns when you were being evaluated as a possible donor? Were you forthright with these concerns? Or, did you conceal information about these issues, or downplay them, in order to be selected? Were there any ways that you deceived evaluators about anything for fear that it might keep you from being selected if you were completely truthful?
4. What were your psychological, or emotional, experiences after donation?  
Early: 0-60 days?  
Intermediate: 2 to 12 months?  
Longer-term: 1 or more years?
5. How would you describe the most important positive experiences or emotions for you following your kidney donation?
6. How would you describe the most important negative experiences or emotions following your kidney donation (e.g. depressive symptoms)?
7. In retrospect, would you have made the same decision to donate? If yes, why? If no, why?

## Appendix C: Informed Consent Form

**CONSENT TO PARTICIPATE IN RESEARCH**

Name of Study Subject: \_\_\_\_\_

**Impression Management and Psychological Reactions  
of Living Kidney Donors**

You are invited to take part in this research study. This form tells you why this research study is being done, what will happen in the research study, possible risks and benefits to you, your choices, and other important information. If there is anything that you do not understand, please ask questions. Then you can decide if you want to join this study or not.

**A1. INTRODUCTION – WHY ARE WE ASKING YOU ABOUT THIS STUDY?**

You are being invited to participate in this research study because you have donated a kidney to enrich the life of another person and we are trying to learn more about your experiences so that we may use this information to better understand and support future donors. We are conducting individual phone surveys and focus groups, which are group discussions that gather together people with similar experiences to discuss a specific topic of interest.

A total of about 50 to 75 people are expected to participate in this study who have donated a kidney.

The Director of the study is Rebecca C. Anderson PhD. A study coordinator, Lee Hildebrand M.A., will coordinate the study under the supervision of the Director, Rebecca C. Anderson PhD. You can ask who these people are.

**A2. DO I HAVE TO BE IN THIS STUDY?**

You can decide whether to take part in this study or not. You are free to say yes or no. Even if you join this study, you do not have to stay in it. You may stop at any time.

**A3. WHY IS THIS RESEARCH STUDY BEING DONE?**

In this study we want to find out the level of disclosure of potential living kidney donors during the evaluation phase prior to being selected as an appropriate donor candidate. We also want to explore the psychological reactions of kidney donors post donation. The only way to find this out is survey by phone and to meet with former living kidney donors in a focus group to discuss these experiences.

**B1. WHAT WILL HAPPEN IF I TAKE PART IN THE STUDY?**

We want to make sure to obtain your appropriate consent before any research procedures are started. Your participation is completely voluntary. You will be contacted by telephone to determine if you desire to be involved in the study as a participant. If this is the case, a brief 15 to 20 minute interview will be conducted regarding your experiences as a kidney donor and to answer any questions you have about the study. Then, you may be invited to participate in one of three 90 minute focus groups to share and discuss your experiences with other kidney donors. All focus groups will consist of participants who donated a kidney in the last 1 to 6 years. Prior to each focus group, a reception will be hosted for you with food and beverages provided during a time of greeting. Following this, the focus group will commence with the 6 to 8 members and a group facilitator. At the end of each focus group, a 15 minute time of debriefing will be conducted by the facilitator to address any questions or reactions to this process. If participants want additional time to talk about their donation experiences or their reactions to the group, they will be able to meet with the facilitator of the focus groups.

### **Video recording:**

Focus groups will be videotaped and the video file will be stored on a password-protected computer. An abridged transcript of the video content will be performed by the project coordinator. When the study is complete and final results are written, the video files for each focus group will be permanently erased. Survey data will be coded/de-identified and all data will be password protected.

Initial either 1 or 2:

1. \_\_\_\_\_ I do not want to be audio/ video recorded in this study. This means that I cannot participate in the study.

**Stop here** and speak to Rebecca C. Anderson. Do not sign this form.

2. \_\_\_\_\_ I agree to be audio/ video recorded in this study.

### **B2. HOW LONG WILL I BE IN THE STUDY?**

⇒ You will be surveyed for approximately 15 minutes via telephone. If you participate in a focus group it will last for about two hours as part of a reception and group discussion with fellow kidney donors. You will have no further commitments beyond this point.

### **B3. CAN I STOP BEING IN THE STUDY?**

You are free to quit the study at any time. If you are thinking about quitting, please tell the study director.

The study director may take you out of this study at any time. This would happen if:

- They think it is in your best interest.
- You do not follow the study rules.
- The whole study is stopped.

If this happens, the study director will tell you.

**B4. ARE THERE ANY SPECIAL INSTRUCTIONS WHILE I AM IN THE STUDY?**

The primary instructions are simply to honestly share your experiences as a kidney donor and to demonstrate mutual respect for the experiences of others in your focus group, as well as maintaining the confidentiality of your fellow group members.

**C1. WHAT RISKS OR PROBLEMS CAN I EXPECT FROM THE STUDY?**

We watch everyone in the study for unexpected problems. You need to tell the study director or a member of the study team immediately if you experience any problems.

There are no known risks associated with participation in the brief survey or a focus group discussion. You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and await the next question, or you may stop immediately. If you feel that you need follow-up afterward to talk about anything, this will be provided by the principal investigator.

Another risk may be loss of confidentiality. Every effort will be made to keep your study records confidential but we cannot guarantee it. All your data will be assigned an arbitrary code number rather than using your name or other information that could identify you as an individual. When the results of the study are published, you will not be identified by name. Once an abridged transcript of the video is performed and all data are collected and analyzed the video will be destroyed. All focus group participants are instructed to keep discussions confidential. However, the researcher cannot guarantee that all focus group participants will respect everyone's confidentiality.

**C4. ARE THERE ANY BENEFITS TO TAKING PART IN THE STUDY?**

⇒ “This study may or may not help you, but we hope the information from this study will help us provide better psychological health services for living kidney donors. We also hope that you gain benefits from having the opportunity to share your experiences and hear the experiences of other kidney donors.

**D1. ARE THERE ANY COSTS TO BEING IN THE STUDY?**

⇒ There are no costs to you for any of the visits or services you receive in this study.

**D2. WILL I BE PAID FOR PARTICIPATING IN THE STUDY?**

⇒ There is no payment for being in this study but we will be providing a reception for you with food prior to the focus group.

**D3. WHAT OTHER CHOICES DO I HAVE?**

You do not have to join this study. You are free to say yes or no.

**D4. WILL I BE GIVEN NEW INFORMATION ABOUT THE STUDY?**

If we learn any important new information about the brief phone survey or focus groups that might change your mind about being in the study, we will tell you about it right away. You can then decide if you want to stay in the study.

**D5. WHAT HAPPENS IF I AM HARMED BECAUSE I TOOK PART IN THE STUDY?**

No funds have been set aside to pay any costs if you are harmed because of this study. If you think that you were harmed because of this study, let the study director know right away by calling the transplant center. By signing this form, you do not give up your right to seek payment for harm you receive while participating in this study.

**D6. WHO CAN ANSWER MY QUESTIONS ABOUT THE STUDY?**

- If you have more questions about this study at any time, you can call Rebecca C. Anderson PhD or Lee Hildebrand M.A. at the transplant center.
- If you have questions about your rights as a study participant, or want to report any problems or complaints, you can call the Hospital Research Subject Advocate.

**E. PERMISSION TO COLLECT, USE AND SHARE HEALTH INFORMATION**

**E1. What health information will be collected and used for this study?**

To do this research study, we need your permission to collect and use some health information from you, or you cannot be in the study. This information may come from questions we ask or forms we ask you to fill out, as described below. We will only collect and use information needed for the study.

**The health information we will collect and use for this study is:**

- ⇒ The date that you donated a kidney
- ⇒ What your relationship is to the kidney recipient
- ⇒ Discussion about your pre-donation evaluation experiences and post-donation psychological reactions to your donation.

**E2. Who will see the health information collected for this study?**

We will make every effort to protect the information and keep it confidential. The only people allowed to handle your health information are those on the study team, those on the Institutional Review Board (IRB) and those who check on the research activities to make sure the hospital's rules are followed.

We will not use your personal health information for a different study without the permission of a hospital research review board. Once all personal identification is removed, the information might be used or released for other purposes without asking you. Results of the study may be presented in public talks or written articles, but no information will be presented that identifies you.

**E3. What are the risks of sharing this health information?**

One risk of taking part in a research study is that more people will handle your personal health information collected for this study. While the study team makes every effort to keep the information confidential, it is possible that an unauthorized person might see it. Depending on the kind of information being collected, it might be used in a way that could embarrass you or affect your ability to get insurance. If you have questions, you can talk to the study director about whether this could apply to you.

***E4. How long will you keep the health information for this study?***

*If you sign this form, we plan to keep your information that is de-identified without any end-date in case we need to check it again for this study. However, we will destroy the video for each of the focus groups at the completion of the study.*

**E5. Can I cancel my permission to share this health information?**

If you change your mind later and do not want us to collect or share your health information, you need to send a letter to [Rebecca C. Anderson PhD]. The letter must say that you have changed your mind and do not want the researcher to collect and share your health information. At that time, we may decide that you cannot continue to be part of the study. We may still use the information we have already collected. If your health information is no longer identified as yours, it is not possible to remove it from the study.

**CONSENT TO PARTICIPATE IN THE STUDY**

**By signing my name below, I confirm the following:**

- I have read (or had read to me) this entire consent document. All of my questions have been answered to my satisfaction.
- The study's purpose, procedures, risks and possible benefits have been explained to me.
- I agree to let the study team use and share the information gathered for this study.
- I voluntarily agree to participate in this research study. I agree to follow the study procedures as directed. I have been told that I can stop at any time.
- I agree to allow video recording in this research study
- I may ask that the recorder be turned off at any point during the study if there is something that I do not want recorded.

**IMPORTANT:** You will receive a signed and dated copy of this Consent Form. Please keep it where you can find it easily. It will help you remember what we discussed today.

<b>Subject's Name</b> <i>please print</i>	<b>Subject's Signature</b>	<b>Date OR Date/Time</b>
<b>Name of Legally Authorized Representative</b> (if applicable) <i>please print</i>	<b>Signature of Legally Authorized Representative</b>	<b>Date</b>
<b>Name of Witness</b> (if applicable) <i>please print</i> (for short form consent process, or consent of blind or illiterate subject)	<b>Signature of Witness</b>	<b>Date</b>

<b>Name of Principal Investigator</b> <i>please print</i> <input type="checkbox"/> I participated in consent process <input type="checkbox"/> I acknowledge enrollment of this subject into the study	<b>Signature of Principal Investigator</b>	<b>Date</b>