

Impact on Living Kidney Donors: Quality of Life, Self-Image and Family Dynamics



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The demand for donated organs continues to be much greater than the supply of organs available. The demand for kidney donation has risen to a staggering, all time high, with over 62,000 patients awaiting transplantation in the United States (United Network For Organ Sharing [UNOS], 2005). In 1997, 11,701 kidney transplants were performed with 3,927 or 33.6% from living related or non-related donors. By 2001, the number of living kidney donors had increased, with organs for 6,035 of the 14,263 transplants performed (42.3%) coming from living related or non-related donors. The numbers in 2004 were very similar with 16,003 kidney transplants performed and 6,647 or 41.5% of the organs donated by living donors (UNOS, 2005).

Most transplant centers have responded to the growing need for organs by expanding the living donor options. These now include both donors that are living related (i.e., by blood, which consists of any living relative [parents, siblings, aunts, uncles, cousins etc.]) and non-related

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Living donation is encouraged because of better graft survival for recipients. This study assesses the impact of living kidney donation on the donor's quality of life, self-image, and family dynamics after the donation occurred. A donor questionnaire and the SF-12 Health Survey were sent to kidney donors whose donation was performed at a community transplant center. The questionnaire assessed the donors' feelings regarding the decision to donate, family dynamics, and medical and emotional preparation. Study findings were that 93% experienced intense recipient gratitude, 91% would donate again, 81% would encourage others to donate, and 31% felt there was a negative health impact. In conclusion, kidney donors were satisfied with their decision to donate; however, more psychological preparation for surgery and consistent follow-up would enhance the donation process.

Goal

To increase understanding of the impact of living kidney donation on the donor.

Objectives

1. List the impacts on life and psychological well-being that need to be considered when discussing living organ donation with a possible donor.
2. Describe the impact found in this study on donors participating in a living kidney donation.
3. Summarize the suggestions made to ensure positive perceptions in living organ donors of their experience.

(i.e., spouses, friends, and acquaintances) between the ages of 18 and 65. These donors must share, at a minimum, blood type compatibility with the recipient.

A new trend in living kidney donation is living donor exchange programs. These programs involve the exchange of living kidney donors between donor-recipient pairs. When two recipients have willing living related donors who have been

found not to be compatible with the original recipient, but compatible with the recipient of the other pair, the donors can be "swapped." These donor and recipient pairs must have very similar conditions, such as age, number of antigen matches, physical size, and a completely negative cross match, in order to exchange donors. The donor and recipient information is entered into a computer database and carefully matched. The donation

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The Nephrology Nursing Certification Commission (NNCC) requires 60 contact hours for each recertification period for all nephrology nurses. Forty-five of these 60 hours must be specific to nephrology nursing practice. This CE article may be applied to the 45 required contact hours in nephrology nursing.

is kept anonymous between both sets of donors and recipients. The surgeries for both pair exchanges are done on the same day to assure that both donations and transplants occur. Although the numbers remain small, the success rate has been reported as good (Delmonico, 2004). It is likely that we will see more of this type of donation within the next couple of years. Currently, two states, Maryland and Ohio, have working exchange programs.

Living kidney donation has been part of kidney transplant programs for over 50 years. Interest in living organ donation is related to the potential for reducing the current organ shortage, shortening the wait time to receive an organ, permitting timing of surgery to optimize the recipient's health, enabling identification of donors with the greatest histocompatibility, and improving function for the transplanted kidney postoperatively (Corley, Elswick, Sargeant, & Scott, 2000). For these reasons, living related and non-related kidney donations are advantageous to recipients. The limited number of cadaver organs available in this country makes the need for living organ donors very significant. Interest in living related and non-related organ donation has broadened from kidney donation to lung, liver, and bone marrow donation (Simmons, Schimmel, & Butterworth, 1993).

Due to the rise in end stage organ failure across this country and the critical need for organs, there has been an increase in public awareness and education regarding donation. Individuals willing to make a living kidney donation are stepping forward and inquiring about organ donation not only for their family members but also for friends, acquaintances, and sometimes strangers. There are many motivators for wanting to become a living donor such as altruism, love, guilt, shame, family obligation, personal responsibility, and gaining family status.

The living donation process is evaluated thoroughly by the trans-

plant team. The living donor is screened to be sure that there is no undue pressure from family members, the recipient, or friends and that money or gifts are not offered to help persuade or force the donor to proceed with donation. Donation has attempted to remain an altruistic process throughout its 50-year history.

The purpose of this study was to replicate a study of donor patients at a large urban transplant center, which assessed how living kidney donors view their quality of life after donation as well as self-image and family dynamics (Schover, Strem, Boparai, Duriak & Novick, 1997). The study questionnaire included two scales that measured positive and negative motivators that influenced the decision to donate. The SF-12 Health Survey was included along with a donor questionnaire to determine how donors felt about the impact of donation and its effect on their physical health (Ware, Kosinski, & Keller, 1996).

Review of the Literature

The practice of living organ donation dates back to the early 1950s with the start of successful transplantation. It has always been a source of discussion for ethical debate and a dilemma in the medical community. Historically, transplantation with organs from living donors has been performed most frequently with kidneys. As current procedures for living donor segmented liver and lung transplantation gain in familiarity and practice, the answers to the questions raised by kidney transplantation using organs from living donors will undoubtedly serve as a model for all living donation transplants (Russell & Jacob, 1993).

The decision to donate has been studied since that start of living kidney donation. Eisendrath, Guttman, and Murray (1969), in one of the first living donor studies ever completed, noted that donors often felt "called" to donate their kidney. Schover and colleagues (1997) found that donors

volunteered without being asked to donate in 85% of cases, recipients solicited the donation in 9%, and other family members or medical personnel asked the donor in 3%. Simmons, Klein, and Simmons (1997) provided an important construct for understanding the dynamics of the donor's decision-making process by breaking it down into three characteristic models: (a) moral decision making, which reflects a seemingly spontaneous choice with no deliberation; (b) deliberation and conscious choice; and (c) postponement, in which a decision is not made until no conscious choice is available (i.e., the individual is either ruled out for medical reasons or becomes a donor when everyone else is ruled out).

The literature has shown that the majority of living donors make the decision to donate with ease or in a spontaneous fashion (Russell & Jacob, 1993; Schover et al., 1997) and report that they do not have any trouble making the decision to donate to their loved one (Schover et al., 1997). Many donors viewed their situation as one they could or would not refuse. In addition, almost all donors felt that they would donate again if given the opportunity.

Living kidney donation has been scrutinized for its ethical and moral issues. In the early years of the procedure, when legal questions arose as to whether live organ donation constituted assault on the donor, a court decision in Massachusetts was reversed on the basis of the psychological and spiritual benefit to be obtained by the child donor (a twin) for being able to save his brother's life (Harrison & Bennett, 1977). Concern has also been raised about whether living donors are always completely informed about the risks that are involved. Russell and Jacob (1993) reported that potential donors have a tendency not to "hear" the risks as stated by health professionals. Donors, in all good faith, might say yes to donating a kidney without really understanding the risks involved. A family member's life

potentially being at stake is a crucial emotional factor against which other risks are diminished in intensity. According to Russell and Jacob (1993), while negative psychological side effects have been reported (including depression and family conflict), these risks are generally under-emphasized to potential donors. Merely raising the issue of live organ donation can evoke powerful psychological processes beyond the potential donor's voluntary control and leave little room for refusal without psychological cost (Russell & Jacob, 1993).

Surgical, financial, and psychological risks to living donors have been reported as being minimal (Corley et al., 2000). The majority of living donors report very positive outcomes after donation including their physical and emotional status (Ciszek, Paczek, & Rowinski, 2003). Medical risks to living donors include conditions potentially exacerbated by the loss of one kidney, surgical technical accidents, pulmonary embolism, infection, and anesthesia risks. Psychological reaction also needs to be considered with all living donors. In almost all reported living donor studies, donors viewed the overall experience as being very positive and meaningful and clearly stated that they would choose to donate again. In a study of a group of potential living related donors and recipients, Wilson, Stickel, Hayes, and Harris (1968) concluded that all potential donors were well informed and their concerns were not any greater than those experienced by patients undergoing elective surgery. Corley and colleagues (2000) found that negative attitudes affecting the relationships of living donors with their recipients occurred in a small percentage of cases and were more likely when the transplant was not successful. It has also been reported that related donor-recipient relationships are closer than recipient relationships with related non-donors (Gouge, Moore, Bremer, McCauly, & Johnson, 1990).

Mild depression and family problems have been the most extensively documented negative psychosocial issues. The majority of these were related to graft failure and recipient loss after transplantation. Financial difficulties for donors has also been noted in the research (Schover et al., 1997).

Quality of life issues have been studied in regard to living kidney donors. According to Ciszek, Paczek, and Rowinski (2003), kidney donors have been reported to have enhanced life quality and self-esteem. Other quality of life studies (Corley et al., 2000, Gouge et al., 1990) have also shown that donors were generally positive overall about donation, but that it did not enhance their overall quality of life. However, Gouge et al. (1990) did show that the overall quality of life of living donors was similar to the national norms. Several surveys of kidney donors have noted that the majority are satisfied with the decision at follow-up, with only a minority perceiving negative psychological, health or financial consequences (Schover et al., 1997).

Family relationships play an important and unique role in living kidney donation. It is often difficult for potential recipients to ask family members for a kidney, but in most cases, family members offer to donate (Hilton & Starzomski, 1994). Many times, more than one family member offers to donate and the best choice is based on blood compatibility, antigen matches, social evaluation and final crossmatch results with the recipient. Family members may insist that they be chosen as the best donor. Many are close to the recipient, want to become closer to the recipient, or want to prove themselves to the recipient or family. Studies have shown that, generally, the donor does feel somewhat close to the recipient (Corley et al., 2000; Schover et al., 1997).

Conflict can also be seen within the family when it comes to donation. Family members can feel angry

about donating. They may feel that the recipient might not take care of the donated kidney or they may feel that their donation is expected of them or that something should be given in return. Other family members may feel jealous of the selected donor or other loved ones may not want the selected donor to donate for fear of losing them or fear associated risk with donation.

Despite the possible conflict or stress that might be associated with donation, most potential donors as well as recipients feel very comfortable with the selected donor. Studies have shown that most relationships improve somewhat after transplantation (Schover et al., 1997; Corley et al., 2000).

Methods

This study replicated a study by Schover et al. (1997). Subjects invited to participate in this study included all surviving, living kidney donors whose donation occurred at Akron City Hospital, Summa Health System Hospitals since the start of the kidney transplant program in 1967 ($n = 165$). A Kidney Donor Follow-up Questionnaire and a Medical Outcomes Study Short-Form Health Survey (SF-12), a standardized measure of health status including quality of life, were used.

The Kidney Donor Follow-up Questionnaire included 41 questions concerning demographic information and assessed donor perceptions of the medical status of the kidney recipient and graft, the decision to donate, the impact on family relationships before and after donation, interactions with the medical team, and the impact of donation on health and finances. The Kidney Donor Follow-up Questionnaire also contained a 6-item positive attitude scale and a 6-item negative attitude scale which had a 4-point Likert response of item importance. Donors were also asked to rate whether they would choose to donate again and whether they would encourage others to donate.

The reliability of the Kidney Donor Follow-up Questionnaire measuring positive versus negative attitudes toward kidney donation was established in the original study (Schover et al., 1997). Cronbach's alpha was calculated to measure internal reliability for the two attitude scales. The items within the positive scale had a Cronbach alpha of 0.716 and the negative scale had a Cronbach alpha of 0.766. Scores for each scale ranged from 4 to 24, with lower scores indicating more importance of the statements to the donor. The two scales were significantly correlated ($r = 0.26, p = 0.001$).

Donors also completed the Medical Outcomes Study Short-Form Health Survey (SF-12), a brief measure of health status. This 12-item questionnaire was developed from the larger SF-36 Health Survey to yield a health status measure that includes physical and mental factors as well as quality of life (Ware et al., 1996). The shortened tool has been validated in samples of the general population as well as patients with many conditions including, but not limited to stroke, Parkinson's disease, and congestive heart failure, and in longitudinal studies (Jenkinson et al., 1997). Test-retest reliability of the two parts of the SF-12 was 0.89 and 0.76 (Ware et al., 1996). For this study, health status was used as a measure of the patient's overall condition.

Of the 165 living related donors identified as potential study participants, 119 were located. The remaining 46 donors could not be located or had died from donation unrelated causes. An invitation to participate along with the Kidney Donor Follow-up Questionnaire and the SF-12 were mailed to these 119 donors. If the questionnaire was not returned within 6 weeks, a reminder postcard was sent. Donor names were not on the questionnaires, but they were coded for demographic and time since donation information. Donors were assured that their responses were confidential. Return of the survey implied consent to participate.

Table 1
Demographic Information of Donors (n = 87)

Age average years (SD)	46.2 (11.35)
Range	25 - 70
Percentage (Frequency)	
Gender - % female	73.6 (64)
Marital status	
Married	72.1 (62)
Divorced	12.8 (11)
Widowed	2.3 (2)
Single	12.8 (11)
Race	
White	82.6 (71)
Black	12.8 (11)
Asian American	1.2 (1)
Native American	3.5 (3)
Education	
Less than high school	6.9 (6)
High school diploma	41.4 (36)
Some college	31.1 (27)
4 year degree	10.3 (9)
Post graduate degree	10.3 (9)

Results

Eighty-seven surveys were returned for a 73% response rate. Demographic information is provided in Table 1. The majority of the donors (75%) were employed at the time of the survey, 6% were retired, and 2% were disabled. The interval since donation ranged from 6 months to 31 years with an average of 7.4 years and a standard deviation of 5.9 at time of data collection.

The characteristics of the donations are described in Table 2. Seventy-one percent of the donors believed that they were the best kidney match for their recipient. Only 5% of the donors reported being pressured by family members to donate, but 24% were asked by someone to remove themselves from the donation process. It was reported that the medical team offered the

donors a medical reason to ease the impact if they chose to refuse donation in 43% of the cases.

Retrospectively, 71% of donors believed that the relationship with their recipient before donation was close while 28% believed that the relationship was somewhat close to distant. Some donors (11%) perceived that there was some noted tension or conflict with the recipient. The donors' perception of the family's closeness was similar; 66% felt close and warm while 34% felt somewhat close to distant. Conflict within the family was reported by 25% of the donors.

Forty-two percent of the donors reported a much closer relationship with the recipient after donation, while 29% reported feeling somewhat closer, and 3% reported a strain in the relationship. Most of the donors (89%) believed that the recipient did

Table 2
Characteristics of Donation (*n* = 87)

Characteristic	Percentage (Frequency)
Donor-Recipient Relationship	
Parent to child	23.0% (20)
Sibling to sibling	43.7% (38)
Child to parent	13.8% (12)
Spouse to spouse	11.5% (10)
Non-related	8.0% (7)
Donation Outcome	
Working well	74.7% (65)
Working but not well	2.3% (2)
Failed on dialysis	17.2% (15)
Died in kidney failure	2.3% (2)
Died with functioning kidney	3.4% (3)
Donor Decision	
Volunteered	87.2% (75)
Asked by recipient	7.0% (6)
Asked by family	2.3% (2)
Asked by medical team	3.5% (3)
Decision Difficulty	
Difficult with many doubts	5.9% (5)
Somewhat difficult with few doubts	11.8% (10)
Easy required little thought	82.3% (70)
Pain from Surgery	
More painful than expected	37.6% (32)
As painful as expected	43.5% (37)
Less painful than expected	18.8% (16)
Financial burden	
No problem	77.4% (65)
Moderate problem	19.0% (16)
Severe problem	3.6% (3)

the very best to maintain a healthy transplanted kidney, but 8% believed the recipient could have worked harder to maintain a healthy lifestyle. Three percent of donors felt that the recipient's bad health habits led to the failure of the donated kidney.

Donors reported financial problems as a minimal consequence of donation. Only 19% of donors had moderate problems, while 4% reported severe financial consequences. Severe problems consisted of loss of work, loss of income, and mounting bills that they were not able to pay. Seven donors reported that donation had a negative impact on their ability to get insurance coverage.

Donors rated the education received from the medical team prior to surgery as good preparation (*n* = 71), needed improved preparation (*n* = 11), or as not enough preparation for the experience (*n* = 4). Donors reported that they felt they were treated special by the medical team after the donation surgery in 55% of the cases, 8% felt that they were ignored, and the remaining donors felt they were treated like any other patient.

The donation process was physically stressful for 49% of the donors, and the donation surgery and recovery was more painful than expected for 38% of the donors. Eleven per-

cent of the donors reported mild depression and 2% reported disappointment related to the surgery/donation. Thirty-one percent of the donors felt that there was some negative impact on their health, and 35% occasionally worried about having only one kidney. After donation, some donors had developed health problems such as hypertension (*n* = 11), kidney disease (*n* = 1) and diabetes (*n* = 3).

The positive attitude scale of the Kidney Donor Followup Questionnaire had a Cronbach's alpha of 0.71, and the negative attitude scale had a Cronbach's alpha of 0.74. The two scales were significantly correlated ($r = -0.36$, $p = .0016$). All donors ranked improvement to recipient's quality of life as very important, and nearly all donors (92%) ranked greater love for the recipient by important family members as not at all important (see Table 3). A significant correlation was found between the positive attitude scale and the experience of being a donor ($r = -0.23$, $p = .037$). The direction of the correlation indicated that donors who ranked positive reasons for donation as very important were also likely to rank the emotional experience of donation as what they had expected. Donors that ranked negative factors as very important in their decision-making process indicated that they would still decide to donate if they could do it over again ($r = -0.31$, $p = .006$). The fear that giving up one kidney might damage the donor's health was the most influential negative factor, with 36% of donors ranking it as at least somewhat important.

Sixty-two percent of the donors in this sample rated their current health as very good to excellent. The average standardized physical component summary scale score of the SF-12 for this sample was 51.5 with a standard deviation of 7.3, which is slightly higher than the norm of the general U.S. population average score of 50.12 (Ware, Kosinski, & Keller, 1998). The majority of the participants (75%) reported not being limited at all in physical functions,

Table 3
Donors' Attitudes Toward Kidney Donation (n = 87)

	Very Important %	Somewhat Important %	Not Very Important %	Not Important %
Positive Attitude Statements				
Save the life of someone I love dearly	97.7	2.3		
Feel that I did the right thing	68.6	18.6	7.0	5.8
Feel that I am a good person	25.6	19.8	20.9	33.7
Have approval of my family	21.2	14.1	18.8	45.9
Improve my recipient's quality of life	100			
Feel closer to my recipient emotionally	31.8	24.7	21.2	22.4
Negative Attitude Statements				
Fear giving up one kidney might shorten my lifespan	8.1	16.3	30.2	45.3
Fear that giving up one kidney might damage my health	9.4	27.1	29.4	34.1
Concern that some family/friends disapproved of donation	1.2	9.4	14.1	75.3
Belief that recipients kidney failure was partly due to bad health habits	6.8	13.5	14.9	64.8
Belief that some important family members loved recipient more than me	1.2	1.2	5.9	91.7
History of anger/conflict in relationship with recipient	3.7	7.4	9.9	79.0

but 9% reported that bodily pain interfered with their normal work quite a bit of the time. The average standardized mental health component summary scale score for this group of donors was 50.6 with a standard deviation of 9.21, which again is slightly above the U.S. general population norm of 50.04. Only one person reported feeling downhearted and blue all of the time, while 71% reported feeling this way little to none of the time.

For the donors whose recipients died (n = 5) or had graft failure (n = 15), 90% of them felt at peace with the donation process and only one donor wished that he or she had not donated the kidney. Forty-five percent of these donors reported that the recipient's death/failure was more devastating because of the donation. Sixteen of the 20 donors whose recipient's outcome was failure or death

reported that the transplant medical team should offer mental health help in those cases. Table 4 demonstrates comparisons between successful outcome donors and failed outcome donors on satisfaction items. These groups were not significantly different on donor satisfaction.

Overall, donors were satisfied with their decision to donate. Ninety-one percent of the donors reported that if they could go back, knowing what they know now, they would make the same decision to donate. Even those that ranked the negative factors of the decision-making process as important reported that they would encourage another person to donate ($r = -0.24, p = .039$).

Discussion

The results of this study indicate that 87% of the donors volunteered

without being asked and 82% thought it was an easy decision to make. This is consistent with the findings of the original study by Schover et al. (1997) in which 85% of the donors volunteered without being asked to donate and 82% thought it an easy decision.

Donor satisfaction was high in both study samples. In the Schover et al. (1997) study, when asked if they would donate again with their current knowledge about the donation process, 90% indicated definitely would donate again, 8% indicated probably, and 2% reported they would probably not donate again. In the current study, 91% of participants reported that they would definitely donate again even with their current knowledge, 7% indicated they would probably donate again, and 2% reported they probably would not donate again. In the original study 83% of the donors indicat-

Table 4
Satisfaction Comparisons between Donors whose Donated Kidney was Successful (n = 67) and Donors whose Donated Kidney Failed (n = 20)

Satisfaction Item	Graft Successful %	Graft Failure %	p value*
Would make choice to donate again			.057
Definitely	94.0	80	
Any doubt	6.0	20	
Advice to future donors			.88
Encourage strongly	81.5	80	
Less encouragement to discouragement	18.5	20	

Note: * Using chi-square test, significance at $p = .05$ level

ed they would strongly encourage someone to donate, and 81% of the donors surveyed in this study reported they would strongly encourage someone to donate.

Family dynamics reported in the Schover et al. (1997) study and this study were very similar as well. Seventy-two percent of donors from both studies reported a close and warm relationship with the recipient. Seventy-one percent of donors in the original study reported close and warm family relationships, while 66% of donors in this study reported close family relationships. Family conflict was reported by 22% of the donors in the original study and 25% of the donors in this study.

As the demand for organs continues to grow in this country, it is important to continue to assess how living donors are making their decisions as well as the consequences these decisions have on the donor at the time of donation and in his future. Are there psychological factors, physiological factors, social issues, or financial deterrents of which we need to be aware? Further work with living organ donors will help answer these questions.

Nursing Implications

Given the low number of cadaveric donations and the increasing number of successful living donations, nurses will increasingly be working with living donors and their families

who are making decisions about kidney transplant. Nurses have always had a strong commitment to patient education and for the advocacy of patients' rights, both of which will be necessary as they recruit and assist these families in making these decisions.

It is the role of the nurse, throughout the evaluation process, to determine that the potential donor has made an educated and informed decision, without coercion, about donating a kidney to a loved one. Nurses should always encourage donors to express their questions and concerns or any issues that may they may have regarding the donation process. Kidney donors need to have adequate emotional support in making this difficult decision. They need to know that a nurse is available to them and that their conversations are held in strict confidence. They should feel comfortable in discussing any issues without fear or embarrassment.

Continual support and education is needed throughout the transplant/donation process. Nurses need to support the donor and the family, allowing them the necessary time to make the right decision and continually reviewing their risks and options until they have an adequate understanding. Nurses need to supply them with all the necessary educational materials and coordinate opportunities for donors and their families to meet with peers who have already

gone through the process. The need for a comprehensive support program for donors, recipients, and their families has been suggested. It would provide them with a chance to identify problems that may arise before and after transplantation. Donors have expressed the need for long-term follow up, and this option should be implemented. Expanding our knowledge and our assessment tools to help develop ways to better support and understand all the unique and difficult questions that arise during the living kidney donation process will provide a greater appreciation for the "Gift of Life."

Conclusion

The findings of this study indicate that the majority of kidney donors are satisfied with the decision to donate and found it to be a fairly simple decision. Although some negative consequences were noted with the donation, that did not lower overall donor satisfaction. Some donors felt pressure not to donate, while others felt pressure to donate, all related to different family members and having different relationships with them. Only 11% felt that they were in some kind of conflict with their recipient and yet continued to donate. Even with negative aspects of living donation, the overall response was very positive, with 91% stating they would donate again in the same situation and 81% stating they would encour-

age others to donate.

Individuals who decided to donate of his or her own free will were generally very satisfied with the decision to donate. The majority of donors felt a continued sense of closeness with their recipients as well as an enhanced happiness and self-esteem. It is clear that donors need good preparation for the donation process, surgery, and recovery. Donors whose recipient's graft failed reported that the transplant medical team should provide counseling. Long-term follow-up is also necessary, but what this entails is unclear at this time and will need further research to help make that determination. However, continued evaluation of the donors' physical and mental status is essential.

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