



<http://www.looksmart.com/>



<http://www.findarticles.com/>

[FindArticles](#) > [Progress in Transplantation](#) > [Sep 2003](#) > [Article](#) > [Print friendly](#)

Exploring donors' and recipients' attitudes about living donor kidney transplantation

Pradel, Francoise G

Dialysis and kidney transplantation are the 2 methods of treatment available to patients with terminal kidney failure.¹ Compared to dialysis, kidney transplantation offers many advantages to patients including a less restrictive lifestyle, a better quality of life, and lower mortality rates.² Because the demand for kidneys is higher than the supply, a limited number of kidney transplantations are performed every year in the United States. There is a growing interest in living donor kidney transplantation (LDKT) because of its potential to reduce the current kidney shortage. In 2000, 39% of the 13 332 transplanted kidneys were from living donors. In 2001, this number increased to more than 50% with 6081 kidneys transplanted from cadaveric donors and 6499 from living donors.³ There are a number of benefits associated with LDKT compared with cadaveric kidney transplantation: a more thorough evaluation of the kidney, a synchronized surgery schedule for donors and recipients resulting in minimal ischemic damage, and better graft function.⁴

Several factors have the potential to affect the number of LDKTs. Attitudes of healthcare professionals in transplant centers about LDKT have improved dramatically over the years.⁵⁻⁸ Initially restricted to donors genetically related to their recipient, LDKT now expands to genetically unrelated donors such as a spouse, member of the spouse's family, friend, or an adopted family member.⁹ The attitudes of potential living donors and potential recipients can also affect the number of LDKTs. Early studies reveal that potential donors have diverse feelings toward kidney donation such as coercion or fear of not being able to donate.¹⁰ Failures to keep appointments or noncommunication with potential recipients have been described as contributing to potential donors' reluctance to donate.¹¹ A recent survey revealed that, although the majority of donors had a positive attitude about being donors, some expressed negative feelings.¹² For example, 36% of

respondents were worried about their own health and a marginal proportion (2%) regretted their decision to donate a kidney. On the other hand, parents who did not donate a kidney to their child reported less self-esteem, more psychological trauma, and poorer relationships with their child compared with parents who donated a kidney.¹³ On the recipients' side, the search for a kidney can be stressful. Simmons and Klein¹⁴ found that recipients felt they should not ask their relative for a kidney. Requests for a kidney were indirect, thereby allowing potential donors not to respond. This generated a new dynamic within families referred to as "noncommunication." In Japan, recipients were more proactive and solicited their relatives, suggesting that cultural factors may be involved in the request process.¹⁵

An area that has previously been unexplored is the impact of the type of surgical procedure used to remove a kidney from a living donor on the attitudes of potential recipients and potential donors toward LDKT. The open nephrectomy is the classical urologic approach in which the kidney is removed through a wide flank incision along with removal of a rib.¹⁶ Laparoscopic nephrectomy is less invasive than open nephrectomy. Donors whose kidneys are removed with the laparoscopic procedure experience less postoperative pain, shorter hospital stay, and shorter convalescence than donors whose kidney is removed with an open nephrectomy.¹⁷ Moreover, a recent study revealed that the introduction of the laparoscopic procedure was associated with an increase in the rate of living kidney donation.¹⁸ How the laparoscopic procedure affects the decision making of potential donors, donors, potential recipients, and recipients has not been previously explored. The laparoscopic technique is less traumatic for the donor and may increase the willingness of an individual to donate a kidney, as well as increase the acceptance of a living donor by a potential recipient.

The objective of this study was to explore the experience of donors, potential donors, recipients, and potential recipients with regard to LDKT and laparoscopic nephrectomy as a preliminary step in the development of a survey instrument. More specifically, the researchers wanted a better understanding of perceived barriers and benefits of LDKT and laparoscopic nephrectomy.

Methods

Focus group interviews (FGIs) were conducted at the University of Maryland Baltimore. This qualitative approach was chosen to extend our understanding of the experience of

donors and recipients before and after kidney transplantation.

Selection Criteria

Four different groups of adult (older than 18 years) participants were recruited: individuals who were considering kidney donation (potential donors), individuals who had already donated a kidney (donors), patients who needed a kidney (potential recipients), and patients who had received a kidney from a living donor (recipients). All individuals were recruited through the University of Maryland School of Medicine Division of Transplantation. The institutional review board at the university approved this study.

Sample

Potential participants meeting the study eligibility criteria were mailed a letter of invitation from the principal investigator explaining the purpose of the study and asking if they would like to be called to learn more about the study. Subjects had the option to decline further contact by returning a preaddressed, prestamped postcard. Two weeks after the initial mailing, 2 transplant study coordinators contacted potential participants who did not return the postcard. They reiterated the purpose of the study, asked if potential participants had any questions, and whether they would like to participate. Once individuals agreed to participate, a date was scheduled for the FGIs. Twenty-nine of the 161 persons who were contacted agreed to participate. The final study sample consisted of 25 participants because 2 persons could not come on the dates scheduled for the FGIs and 2 did not show up at the time of the FGIs.

Preparation and Implementation of FGIs

A preliminary step was to develop 4 topic guides after a review of the literature and consultation with transplant specialists and the investigators. The topics covered were the decision-making process, the screening phase, the surgical procedure, and life after transplantation. This framework was used only as a starting point for discussion as the main generators of themes were the FGIs. The topic guides were reviewed during debriefing sessions conducted after each round of FGIs. Minor adjustments were made to better reflect themes and issues discussed by participants. For example, the first round of FGIs revealed the importance of social support for both recipients and donors. Therefore,

we added an item addressing that theme in the topic guides for future FGIs.

A training session for the 2 moderators and the 2 note takers in charge of the interviews was implemented before the FGIs. During that session, essential points for moderating FGIs (eg, opening, probing techniques, handling difficult participants) and closing (summarizing the information for confirmation or clarification by the participants) were covered.¹⁹ In addition, the topic guides were reviewed.

We conducted 8 FGIs (2 for each group of participants previously described). Each participant attended only 1 interview. Upon their arrival, participants read and signed an informed consent. Interviews were tape-recorded after verbal consent was obtained.

Analysis

The content analysis was guided by a phenomenological approach, as described by Pattern²⁰:

Identification of key phrases and statements that address the phenomenon of interest;
Interpretation of the meaning of these statements; Inspection of these meanings for what they revealed about the essential, recurring features of the phenomenon being studied;
Offer a tentative statement or definition of the phenomenon in terms of the essential recurring features identified

In this study, the phenomena of interest were LDKT and laparoscopic nephrectomy.

Two researchers performed the analysis independently. Once interviews were transcribed verbatim on a word-processing file, the researchers carefully read the transcripts and identified common and dissident themes reflecting the participants' experiences with LDKT and laparoscopic nephrectomy. They then compared their findings and developed a narrative of the themes including verbatim phrases that best represented the essence of the phenomena.

Results

Twenty-five persons participated in the interviews. Sixteen of the 25 participants were white and 9 were African American. All but 4 participants were involved in genetically

related living donor transplantation, that is, the respective donor or recipient was a sibling, parent, or child. Additional demographic characteristics specific to each group interviewed are displayed in the Table.

There were fewer participants in the potential donor and potential recipient groups than in the donor and recipient groups, mainly because the recruitment procedure that left a short time window between the mailing of the letter of invitation to potential donors and potential recipients and the date for the transplantation. As a consequence, several potential donors and potential recipients did not want to participate because it was a busy and/or a stressful period for them.

Despite the small number (fewer than 4) of participants in 5 of the 8 groups, it was decided to proceed with the interviews. We used the same protocol and topic guides when interviewing participants in the small and large groups. Although, from a methodological standpoint, the small group interviews in this study are not FGIs per se because of the number of attendees; for the sake of clarity, they are referred to as FGIs in the following.

Potential Donors

Decision-Making Process. Potential donors were extremely self-motivated and were not hesitant to give a kidney. One of them had accomplished everything she wanted in her life and felt that it was time for her to take some risk. The main reason for potential donors to give a kidney was that they did not want their relative to endure more suffering: ". . . I had no problem with it at all; I just felt like if I could relieve my sister, the suffering that she was going through. . ."

Participants' discussion also suggests that the pre-transplant phase was stressful. All potential donors worried about being rejected during the screening process. ". . . My biggest concerns are that you're gonna find some stupid little reason not to give it to her. . ."

Besides the fear of not passing the screening phase, potential donors seemed somewhat distressed by the lack of information regarding the period following the removal of their kidney. They worried about temporary restriction of activity and wondered whether they would be able to take care of themselves after discharge or whether they would need a

special diet. They stated that getting more information from the surgeon or from persons who donated a kidney would be helpful. The prospect of living with 1 kidney was not a concern and the likelihood of having a kidney problem afterwards seemed remote or unlikely for potential donors. Although financial costs of the transplantation were not an issue, potential donors felt that they should have received information at an early stage in the screening process that health insurance companies would bear the costs of kidney transplantation.

Laparoscopic Procedure. It was not clear to potential donors whether laparoscopic nephrectomy would be used to remove their kidney, although they recalled having the modalities of this procedure explained to them. Participants felt that only the surgeon would ultimately be able to tell them what technique would be used. These comments suggest that there might be some gaps in the information provided to potential donors about the laparoscopic procedure, and might also reflect a lack of concern from potential donors regarding which type of procedure would actually be used to remove their kidney.

Donors

Decision-Making Process. Donors did not hesitate to donate a kidney. Although the majority of donors had familial responsibilities, they were extremely self-motivated in their decision. They were comforted by the fact that most of the time families supported their decision, although they worried for the families. In one case, other family members volunteered to give a kidney if the initial volunteer did not pass the screening phase. Donors without familial obligations felt that it was appropriate for them to take some risk. According to donors, the possibility for their recipients to have a kidney transplantation was raised by the physician (the family practitioner or the nephrologist), the recipient, or the family. However, the FGIs revealed that donors consistently initiated the discussion regarding LDKT and had to convince recipients that it was a good option. The main reason stated by donors for giving a kidney was that they did not want their relative to endure more suffering. It seems that seeing their relative on dialysis triggered their decision. They wanted to free them from the "machine."

I just wanted to make sure my sister was gonna be here for a little while. . . . How long will she live. . . I don't care if it's one day that she has away from that machine. . . she gets better and gets away from the machine.

For some participants, donating a kidney was in accordance with their religious beliefs. They viewed the kidney donation as living as a true parishioner or responding to God's will. Several participants also mentioned the support they received from their religious community. One participant reported that his church organized a prayer chain all over the country on his and his recipient's behalf.

In one of the FGIs, an African American woman talked about the reluctance of her peers to donate an organ, which she did not understand. The other participant, a white man, was not aware of that issue. Both participants also felt that there was a need to redefine how people consider health, illness, and the heroes in society. They wished that society valued real heroes, such as healthcare professionals involved in organ transplantation. They considered that people's attitude toward others' suffering affects their attitude toward living organ donation or organ donation. They also felt that more should be done to raise public awareness about organ transplantation.

Donors talked about the concerns they had before the removal of their kidneys. For example, it was important for them to stay healthy before the surgery. They were careful before the intervention not to hurt their kidneys. Similar to what potential donors stated, the prospect of living with 1 kidney was not an issue for donors. However, 1 donor explained that she wished she had more information before the transplantation, such as how giving 1 of her kidneys could affect her future pregnancies. None of these concerns had been sufficient to deter these participants from giving a kidney.

Laparoscopic Procedure. All the donors had their kidneys removed with the laparoscopic surgery and explained that once they learned about this procedure, they found it amazing. They also were impressed by their prompt recovery after the surgery. The type of information provided varied among donors. Some received verbal information alone; most received verbal information and watched a videotape. One patient was one of the first patients to have a laparoscopic kidney removal and was informed about the procedure just before entering the operating room. Despite the perceived benefits of the laparoscopic procedure, all participants said that they would also have accepted the open surgery procedure if necessary. There was no fear of experiencing pain or of having a scar: "I was going to do that even if it had been painful because I know I could get over that."

Life After Kidney Removal. Several rewards were associated with the experience of

becoming a live kidney donor: "rebirth" of a loved one, social recognition, and opportunity for taking some time off. The main benefit mentioned by donors related to their satisfaction of seeing the improvement in the quality of life of the recipient. Donors were thrilled by the physical and emotional recovery of the recipient, and there was a sense of accomplishment and pride of helping someone: "Her recovery has been spectacular . . . she's on minimal medication . . . she looks great. . ." "It's an experience of a lifetime; it's very rewarding."

The whole experience strengthened relationships of the donors with their recipients and many of them celebrate the transplantation anniversary. The donors also gained recognition from their coworkers and their religious community.

I even told the people at my church. And one Sunday, the minister got up and said some very lovely things. And they had everybody pray for us. The people who were sitting around me, of course, they turned and hugged and kissed me.

In addition, donors considered the postsurgery period a "cocooning" period during which family and friends took care of them. It was also an opportunity for them to take time off from work, even though they felt they could have resumed work earlier.

Donors also mentioned a few concerns. They resented the physical separation from the recipient while at the hospital and they felt that the follow-up care was minimal. Although donors acknowledged their prompt recovery they felt like they had been deserted by the Healthcare team after giving the kidney.

Potential Recipients

Decision-Making Process. The family, a friend, or a physician initiated the discussion about getting a kidney from a live donor. Potential recipients never raised the issue themselves, nor asked directly for a kidney from persons they knew. One exception was the case of a potential recipient who from the time she was a young girl, knew that a member of her family would give her a kidney when the time arrived. One factor that seemed to motivate potential recipients to seek an organ transplant was their negative attitude toward dialysis. Most participants stated either that they did not want to go on dialysis or that they wanted to go off it: "I don't want to go on a machine"; "Dialysis beats you so much."

Other reasons mentioned were that their health was deteriorating and dialysis was not an option anymore. Potential recipients expressed mixed feelings regarding the origin of the kidney they would prefer to receive. They were worried about receiving a kidney from a cadaveric donor because they were not certain about the health status of the donor. One participant assumed that cadaveric organs were screened for some diseases (hepatitis, human immunodeficiency virus), but she was not certain. Despite these issues, most potential recipients were willing to accept a kidney from a cadaveric donor because they felt they needed a transplant anyway. One potential recipient, who for medical reasons was not eligible for a cadaveric kidney transplant, stated that if he had the choice he would prefer to receive a cadaveric kidney because it would prevent him from taking the kidney of a loved one.

Although potential recipients knew they would have to take several prescription drugs for the rest of their lives after the transplantation, they did not seem to be bothered by that fact because most of them were already on a heavy drug regimen. However, one potential recipient worried about some of the drug side effects that were mentioned to her such as hair loss and hirsutism.

Laparoscopic Procedure. The laparoscopic procedure was viewed positively by potential recipients. Some had previously heard about this type of procedure performed for knee surgery and knew that the recovery was prompt compared with the recovery from a traditional surgical intervention.

Recipients

Decision-Making Process. The decision to seek a kidney transplant was made either by the patient or by a relative (spouse, sibling, child, or friend). The proactive role of patients or their family was sometimes triggered by the nephrologist's reluctance to refer them to a transplant center. Reasons given were that recipients were too old or that they first had to go on dialysis. Consequently, patients or their relatives sought out options other than dialysis. Approaches taken were to consult another nephrologist or to contact a transplant center. For some patients, the nephrologist recommended the transplantation. All recipients but one said that once they found out about the possibility of getting a kidney transplant, they did not ask family members to become a donor. They did not want to impose such a burden on their loved ones. It was a family member or a close

friend who brought up the possibility of becoming a donor. Most recipients said that at that time they felt guilty or embarrassed and first refused the offer. They did not want the potential donor to feel obligated to give a kidney or to have a kidney problem later. Recipients reconsidered their decision because of the insistence of their relative. In the posttransplant period, participants expressed how much they owe to their donor:

Well, there is no way I can repay her. I tried to give her special gifts and she gets mad. . . . She says that's no big deal, you know. I say, you are a special person.

Despite the difficulty of accepting a kidney from a living donor, most recipients agreed that they would have accepted a cadaveric kidney only as a last resort. The main concerns about receiving a cadaveric kidney were that the kidney may not be functional or that the donor may not have been healthy. For example, recipients worried about being infected with hepatitis or human immunodeficiency virus. One participant also talked about not being comfortable receiving a "foreign body." Although other recipients had similar concerns about receiving a kidney from an unknown living donor, they seemed more willing to accept this option compared with accepting a cadaveric kidney. Recipients also preferred to have an organ from a genetically related living donor because it would provide the best match. These findings suggest that there is a hierarchy in the way recipients value and accept a graft. Receiving a kidney from a relative is not impersonal, as opposed to receiving a kidney from an unknown origin. Although the decision to accept a kidney from a relative or a friend is not easy to make, recipients feel that this is the best option for them.

The financial costs of the transplantation could possibly be a major barrier to the recipients' willingness to accept a kidney from a living donor. All recipients agreed that they would never have accepted their relative's or friend's offer if the relative or friend had to pay for the surgery. This finding suggests that one initiative to improve LDKT would be to inform potential recipients that health insurance companies pay for the transplant costs of living donors. This information may also be useful when developing mass awareness campaigns on living kidney donation.

Laparoscopic Procedure. Recipients were relieved to learn that their donors would have their kidneys removed with the laparoscopic procedure, which they thought was less traumatic than the open nephrectomy procedure. However, the type of surgery was not a determining factor in their willingness to accept a kidney from a relative: "It was much

better if it could be done that way, but I guess I would have gone through it anyway."

In some cases, the medical team had not informed recipients that their donors would have their kidneys removed with the laparoscopic procedure. These recipients learned about it from their donors.

Life After Transplantation. Overall, recipients largely benefited from transplantation; most recipients reported a better quality of life. Some recipients referred to transplantation as "a rebirth," and some celebrate this anniversary with their donor. Another benefit of the transplantation for recipients was regaining control of their lives. For example, recipients did not have to plan anymore for the dialysis and they appreciated being able to travel without worrying about finding a dialysis center.

Although the majority of the recipients had a positive experience with the transplantation, the discussion revealed a few drawbacks. Several recipients felt tired and less energetic since the transplantation. However, it was not clear from the transcripts whether participants compared their current health status with their health status when on dialysis or before being on dialysis. They also acknowledged that this loss of energy might be a result of the aging process. Several recipients, aware that their immune system was depressed, were nervous about getting around people with a cold or other contagious diseases. One recipient, whose donor was a friend, also reported emotional strain. The recipient's family members did not offer to be screened and did not seem to understand how emotionally difficult this period was for her. Although the recipient understood and accepted her family's decision not to offer a kidney, she felt that the whole process generated resentment and sadness on both sides.

Discussion

Our findings reveal that potential donors were willing to give a kidney without any feeling of being coerced or need to meet others' expectation. Their decision was mainly motivated by a desire to help a loved one who was suffering. Amazingly, most potential donors worried about not being accepted as a donor during the screening procedure. Overall, donors and potential donors were pleased with their decision to donate a kidney. None of the donors regretted their decision or worried about their health. This is somewhat different from what was found previously in a mailed survey.¹² Reasons for this difference might be the fact that the FGIs involved fewer participants from a

convenience sample, whereas the survey reflected anonymous responses from a representative sample. Another explanation might be the length of time between the kidney donation and the implementation of the studies, which ranged from a few months to 4 years in our study and a few months to 25 years in the survey.

None of the African American participants ever talked about any conflict with their close social environment because of their decision to become a donor or to receive a kidney. This finding adds to the somewhat controversial literature on African American preferences and expectations about organ donation and kidney transplantation.²¹⁻²⁴

All donors in our FGIs had their kidneys removed with the laparoscopic procedure. They were pleased with that procedure because they recovered quickly. However, the laparoscopic procedure was not a factor that influenced their decision to give a kidney. Donors and potential donors unanimously stated that they still would have donated the same had an open nephrectomy been performed instead of the laparoscopic nephrectomy. This needs to be explored further by interviewing donors who had their kidney removed with the traditional open nephrectomy. Similarly, potential recipients and recipients viewed the laparoscopic procedure positively. Recipients' comments suggest that being aware that the donor would have a laparoscopic kidney removal reduced the stress they experienced in the pretransplant phase. When potential recipients initially meet with the transplant team, it may be helpful to inform them that a laparoscopic procedure will be used to remove the kidney from the donor. This could facilitate the acceptance of a kidney from a living donor by potential recipients or even encourage them to ask relatives for a kidney.

Our study unveiled a number of potential barriers to LDKT. For potential recipients, the main barrier to LDKT was their reluctance to request a kidney from a relative or a friend. Potential recipients do not take a proactive role in seeking a living kidney donor because they are concerned about the consequences of a kidney removal on the donor's health. This reluctance to ask for a kidney was observed previously in a survey of patients with end-stage renal disease (ESRD).²⁵ Moreover, once donors have been identified, the decision to accept the kidney was not easily made by potential recipients. Recipients and potential recipients worried about their donors having a kidney problem or needing a kidney in the future. However, the follow-up of living kidney donors over a period of 30 years shows that perioperative and long-term risks for living kidney donors are extremely rare.²⁶ This finding suggests that providing potential recipients with information on risks

of living kidney donation for the donors may alleviate some of their concerns.

Potential recipients and recipients also believed that a kidney from a non-blood-related donor was not as a good match as a kidney from a blood-related donor. There is now evidence that the survival rates for non-blood-related living transplantations are similar to those of living blood-related transplantations.²⁷ Recipients' misperceptions need to be addressed in educational programs targeting potential recipients, their relatives, and the general public.

Another potential barrier relates to the cost of surgery for the donors. Recipients clearly stated that they would not have accepted a kidney from a living donor if the donor had to pay for the kidney removal. Currently, these costs are covered by the potential recipients' health insurance. Most patients are insured under the federally sponsored ESRD Medicare program, which covers the donors' surgery costs. Our findings highlight how crucial health insurance coverage is from a recipient's perspective because it seems to remove one of the barriers to LDKT.

For potential donors, the main barrier seems to be the reluctance of potential recipients to accept the kidney. Another barrier is the lack of awareness in the population at large about LDKT. There is now evidence that the success rate of LDKTs is as good as the success rate of cadaveric kidney transplantation, and that the long-term health outcomes of living donors are good. This may be a good time for public health authorities to inform the public on LDKT. There also was a consensus among potential donors and donors that they needed more information on insurance coverage issues and on short- and long-term physical consequences of the kidney removal. In addition, they expressed the need for better emotional support on the part of the healthcare team and better clinical follow-up in the posttransplant period as was observed elsewhere.²⁸

Finally, a factor that might affect ESRD patients' access to LDKT is the role of healthcare professionals in recommending a LDKT to their patients as an alternative to dialysis. For example, although nephrologists and surgeons view living donor blood-related kidney transplantation positively, nephrologists do not extensively support living unrelated donation.²⁹ They could be reluctant to refer patients to transplant centers because this would result in loss of revenues. Although this area needs to be further explored, a recent analysis of the US Renal Data System revealed that ESRD patients treated in for-profit dialysis centers are less likely to be placed on the waiting list for a

kidney transplant than those treated in not-for-profit dialysis facilities.³⁰

Participants were recruited from a single transplant center and the sample was a convenience sample. Therefore, conclusions and recommendations should be limited to the sample studied. Nonetheless, the breadth of information obtained largely overcomes the lack of generalization of our results. Although referred to as FGIs, several interviews were not FGIs per se because of the small number of participants. Therefore, some of the data obtained may not be as rich as those produced during a typical FGI.

Conclusion

The results of this exploratory study reveal that overall potential donors, donors, potential recipients, and recipients had a positive attitude toward LDKT and laparoscopic nephrectomy. This study also shed light on a number of barriers that had not been previously reported. Donors expressed a concern regarding the lack of awareness about LDKT among the general public. Potential recipients and recipients stated that they would be reluctant to accept a kidney if their donor had to pay for the costs of the kidney removal, and believed that a kidney from a non-blood-related donor was not as good a match as a kidney from a blood-related donor.

Further research should address the attitudes of individuals who have not yet started to think about a transplant or who have not already made their decision to give or accept a kidney. Attitudes of anonymous donors also need to be explored. Such studies could bring a different perspective on individuals' decision to accept or give a kidney.

Acknowledgments

This study was supported by a grant from Roche Laboratories, Inc. The authors would like to acknowledge the assistance of the following persons during data collection and preparation of the manuscript: Rhona Limcangco, Jesse Cooke Jr, Amy Alper, and Julie Ann Stein.

Copyright North American Transplant Coordinators Organization Sep 2003
Provided by ProQuest Information and Learning Company. All rights Reserved.