

Challenges in Kidney Donation Faced by Relatives in Iran: A Qualitative Study

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Abstract

Objective: Kidney donation from a relative is an ideal option for transplantation that would improve the recipients' quality of life. The aim of the present study was to evaluate the challenges in the donation process faced by kidney donors related to patients.

Materials and Methods: This is a descriptive qualitative study that uses a content analysis approach. In this study, 16 relative donors from kidney transplant centers of all the educational hospitals affiliated with Tehran University of Medical Sciences were selected through purposive sampling. Data were collected using face-to-face, in-depth, semi-structured interviews.

Results: The data analysis results led to the extraction of three main themes: initial confrontation, hospitalization, and endless concerns. The second theme of the study had two sub-themes: being ignored and the rights of the donor.

Conclusion: The challenges faced during the donation process were difficulties in performing tests, difficulties during hospitalization, and endless concerns. These challenges eventually become bearable for the donors because of their love for the recipient and because they totally forget themselves and their needs during the donation process.

Keywords: Donation, kidney, challenge, relative, qualitative

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INTRODUCTION

Kidney transplantation is more affordable than dialysis and is associated with a better quality of life and prolonged lifespan for the patients (1, 2). The need for dialysis would be resolved following a successful kidney transplant, which would improve the patients' quality of life (3). There are three main known sources for kidney transplant, including a related living donor (related by blood and by marriage), an unrelated living donor (financial compensation or humanitarian), and brain-dead donor (4). In recent years, the mean interval between being placed on the waiting list and receiving a kidney from a brain-dead donor has significantly increased; this interval is approximately 3-7 years for kidney transplant patients (2, 5). In Iran, because the number of brain-dead donors is much lower than the number of patients

requiring a kidney transplant, the need for living donors is very high (6).

During the past decades, the number of unrelated kidney donors with humanitarian intent has increased in developed countries, but the supply has been lower than the demand, which has led to a severe shortage of kidneys along with an increased mortality rate and increased business incentives for donation and transplant tourism (7). The increased number of unrelated donors with financial compensation has decreased the number of donations from relatives in Iran. However, unrelated donors seeking financial compensation usually have a lower quality of life than related donors, and they mostly regret donation (8). In fact, their main motivation for donation is solving their financial problems (2).



Receiving a kidney from a relative would increase the survival rate of the kidney recipient. In addition, the need for receiving an immunosuppressive regimen after transplant would be decreased in the recipient (9, 10). Therefore, kidney donation from a relative is an ideal option in transplantation that would improve the recipients' quality of life after transplant (11). Although the number of donors is increasing in Iran, few relatives make the decision to donate (12). Furthermore, their manner of encountering donation and also the challenges they face are ambiguous. Theoretical knowledge and information about the process of donation, the steps involved in completing the donation process, and the challenges faced by relative donors, especially first-degree relative donors, are limited. Evaluation of the experience of donors 1 week after donation revealed that the related donors experienced more stress after donation compared with that faced unrelated donors because of their dual roles (being a donor and a relative to the recipient) (13). Because few studies exist on the challenges faced by related donors, the aim of the present study was to evaluate the challenges for related kidney donors in the process of donation.

MATERIALS AND METHODS

The present study was a qualitative study with a conventional content analysis approach for collecting and analyzing data to determine the challenges faced by kidney donors in the process of donation.

Participants

A total of 16 related donors (10 women and 6 men) were selected from kidney transplantation centers of educational hospitals affiliated with Tehran University of Medical Sciences using a purposive sampling method. The inclusion criteria were being >18 years, being related to the recipient, having a favorable physical and mental condition for participating in the study, being willing to participate, and signing the informed consent form. In this study, the age range, gender, family relationship, and duration passed after donation were factors that could be considered to achieve maximum variability.

Data Collection

Data were collected using in-depth semi-structured face-to-face and phone interviews. Data collection lasted for 8 months (May 2015 to October 2015). The duration of the interviews varied from 45 to 90 min. Interviews were recorded using a voice recording device, and the answers were written down verbatim after each session. The main questions in the interview were, "What steps have you completed during the donation process?" and "What challenges did you face during the process of donation?" Furthermore, investigative questions were used during the interviews to clarify the answers of the participants.

This study was adopted from a Ph.D. thesis in nursing. The proposal for this study was approved by the ethics committee of the research council of Tehran University of Medical Sciences (IR.TUMS.REC.1395.2593). The goals and methods of the study

were explained to the participants. Additionally, during the study, participants were allowed to leave without any penalties or losses. Written informed consent was obtained from all the participants. Their permission was obtained for recording of the interviews. Participants were assured that their information would remain confidential.

Statistical Analysis

We analyzed the study data using the qualitative content analysis approach. Content analysis is a scientific data analysis approach in which a researcher reduces and organizes data to explore the symbolic meaning of experiences (14). In the present study, immediately after each interview, we transcribed the interview verbatim and read the transcript several times to gain familiarity with the main ideas of the interview. Next, we divided the text into meaningful units. Subsequently, we condensed the meaningful units for the sake of abstraction and accordingly coded the condensed meaningful units. Finally, we compared the codes with each other and categorized the codes into themes and sub-themes according to their similarities and differences.

Trustworthiness

The study accuracy is one of the important aspects during the process of any qualitative study, which would lead to reader's audit of the facts, effects, and researchers' actions (15). In this study, peer review was used to achieve trustworthiness. Data were coded and categorized by the researchers separately. Then, the obtained themes from the analysis were compared with each other. In case of disagreement about a theme, researchers discussed the issue until achieving a common decision. A member check was also used so that a summary of extracted themes was given to some of the participants to approve them based on their own experiences. Accurate auditing from the very first steps of the study and during data gathering was used to achieve the trustworthiness of the study.

RESULTS

The results of the present study were obtained after analyzing interviews of 16 relative kidney donors; interviews were continued until data saturation. The mean age of the participants was 41 years, and the mean time passed after the donation was 5 years. Other demographic characteristics of the participants are presented in Table 1. Results of data analysis led to the extraction of three main themes: initial confrontation, hospitalization, and endless concerns. The second theme of the study had two sub-themes: being ignored and the rights of the donor. What follows is the meaning of each theme and sub-theme and the direct quotations from the participants.

Initial Confrontation

Initial confrontation means starting the process of donation after making the decision. During the initial confrontation, the donor needed to pass preliminary tests to approve the appropriateness of donation to the relative. Performing the tests was

Characteristics	N (%)
Gender	
Female	6 (37.5)
Male	10 (63.5)
Educational Level	
Elementary	2 (13)
High School Diploma	10 (62)
Bachelor's	4 (25)
Age	
mean±standard deviation	40±3.45
Time after donation	
<1 year	4 (25)
1-5 years	6 (37.5)
>5years	6 (37.5)

one of the longest and most stressful parts of the donation process, and according to the participants, lasted at least 6 months. Most participants complained about the delayed duration of this period. Some of the donors got exhausted during this period and sometimes even regretted their decision to donate. Some participants complained about the lack of a comprehensive systematic program and some about the lack of a supportive system during this period; most participants tolerated significant mental and psychological pressures during this period. Some participants had traveled to Tehran from smaller cities to undergo the preliminary test because of the equipped laboratories in Tehran. They mentioned feelings of loneliness and homesickness, lack of support, and lack of a place of residence. During the first confrontation with donation, most donors believed that the worst and toughest part was performing preliminary tests.

Although donating parents, especially mothers, had patience and provided unconditional love throughout the entire donation process, they experienced restlessness and intolerance during the tests owing to their difficulty and lengthy durations. A mother who donated a kidney to her daughter provided the following statement:

“There was a heart test too, during which I got really tired and confused. I was saying why don't these end? I never thought that it could be so long and tough. I used to think that matching blood types is enough. I was whispering ‘Oh God, please let this stop.’” (Second donor, mother's donation to her daughter)

Some participants also believed that the lengthy period of the tests was threatening their job because they had to take repeated leave of absences for undergoing the tests.

“The time that we spent performing the tests was too long. They delayed the work so much. I was employed, so I had to

take repeated leaves and pay cuts from my work. I was so worried sometimes that I couldn't take it anymore.” (First donor, daughter's donation to her father)

Lengthy test periods, their high cost, repeating various tests, and the ambiguity of the results of the match between the donor and the recipient were some of the challenges and difficulties that donors faced during the donation process, such that some of the participants mentioned considering withdrawal and regretted the decision to donate.

Hospitalization

After passing the long and difficult period of testing, donors would be hospitalized for donations. Participants reported various experiences during this period from their confrontations with physicians and nurses at hospitals. Most participants' interactions during hospitalization and nephrectomy were with nurses, and they experienced little interaction with their physicians. This theme had two sub-themes: being ignored and the rights of the donor.

Being ignored

Most participants in the present study stated that most of their interactions with the physicians were at the early stages while they were being instructed about the preferability of donation from a relative. They believed that they were ignored by the transplantation team after the surgery and kidney donation. Some of the participants mentioned lack of attention and support. Participants believed that nurses mostly paid attention to the recipients, and the donors had not received any special attention before and after the surgery. One of the donors stated as follows:

“Not before the surgery and not even after the surgery the nurses spoke to us about what was going to happen or did anything for us or pay any attention to us; instead, they were mostly focused on the recipients.” (Sixth donor, spouse's donation to the spouse)

While interviewing some of the nurses from the transplant ward, they mentioned that numerous and sensitive care procedures and follow-ups of the recipients were one of the reasons for not paying sufficient attention to the donors. They also mentioned the lack of a standard protective and educational plan and protocol for donors at the hospital environment. Nurses believed that the reasons for not paying sufficient attention and support to the donors were physicians' ignorance toward the donors after donation, lack of a specific position for nurses among the transplantation team, lack of a referring center for donors to perform donation follow-ups, and the health system not paying the donors.

The rights of the donors

In the present study, some of the participants complained about disrespecting the patients and their rights at the time

of their need for attention and emotional and mental support. Most participants were eager to receive information and respect during the process of donation. They expected to receive the minimum rights of the patients; they did not have high expectations from the treatment team. Their expectations following hospitalization were being met, and they were interacted with humanly and obtained correct information from an experienced and aware team.

One of the greatest expectations of the donors during hospitalization was receiving an educational program for improving the quality of life after donation. The participants stated that after the surgery, they had many questions about their health condition, required follow-ups, and consequences of transplantation, but they had not received sufficient answers from the treatment team. According to the donors, prepping the patients before the donation is the duty of the transplant team. They believed that the presence of a counselor and a psychologist before the surgery was one of their rights that was neglected. Regarding psychological counseling, one of the participants stated as follows:

“I wanted to donate my kidney with love and interest, but I was so nervous and stressed. I wanted someone to be there so that I could talk to them and remain calm.” (Tenth donor, sister’s donation to a sibling)

Participants in the present study had very little information before the surgery regarding the possible physical consequences of donation, such as severe pain or nausea and vomiting. They mentioned that they encountered an unbearable pain without being prepared, which caused excessive tension and discomfort for the donors. Furthermore, they had not received an educational program for self-care and postoperative follow-ups.

Endless concerns

Although the donors who were relatives in the present study had willingly decided to donate their kidney, they were worried during the entire process of donation. They believed that only the condition of their worry was changed at different stages of the donation. They also believed that even transplantation could not completely resolve their concerns about the health of their recipient, and it only decreased their concerns. Concerns about blood type incompatibility at the stage of performing the tests, concerns about anesthesia and surgery, and concerns about rejection of the donated kidney were some of the concerns expressed by relative donors. One of the participants stated as follows:

“At the hospital, I was in so much pain, but I wasn’t thinking of myself, I was thinking of my sister. I was worried that her body might reject the kidney or that she might have not come out of anesthesia; I had completely forgotten about myself.” (Eighth donor, sister’s donation to a sibling)

The fear of the rejection of the donated kidney was one of the fears of most of the donors, even years after the donation. This concern was specifically significant among donating parents. Some of the donors even found another relative for donation because of their fear of rejection of the donated kidney.

Another concern of the donors, especially among donating parents, was the side effects of the drugs taken by the patient after transplantation. They believed that because of the administration of immunosuppressive drugs, the patient would be prone to various diseases, and this made them concerned.

A mother, after donating a kidney to her child, expressed the endless difficulties and concerns regarding the donation. She stated that not only are her concerns over but her life is now entangled with concern and anxiety:

“I didn’t think that I still would be so concerned after the transplant, but I notice that I’m always worried and anxious. I fear that my child could get sick more than others, and that’s because of the drugs she is taking. On the other hand, I constantly think what if her body rejects the kidney, then what should I do? I don’t forget even for a second. It is like a concern, and anxiety has become a part of me.” (Second donor, mother’s donation to her daughter)

DISCUSSION

Participants in the present study stated that the challenges that they faced during the donation process were difficulties in performing tests, difficulties during hospitalization, and endless concerns. To obtain the final approval and confirmation of being a suitable candidate for donation, the donors should pass all the necessary tests. In the present study, the testing stage was one of the longest and most stressful stages during the donation process. The results of a previous study showed that the donors reported the stage of performing the tests as the toughest, longest, and worst part of the donation process (16). They had experienced a significant amount of stress and anxiety about the results of the tests, which even made some of them reconsider their decision about the donation (1). Results of the study also revealed that performing the tests causes stress and anxiety for the donors, and referring to the laboratory and performing the tests before the donation is an uncomfortable experience for them. Because of the lack of coordination, delay, and wasting of time on testing, the testing stage was reported as stressful for donors (17). Some participants in the present study reported exhaustion at this stage and even reconsidered their decision to donate, but eventually, despite all the difficulties and lengthiness of the testing stage, they completed this process and donated their kidney because of their feelings of responsibility, along with love and motivation.

Some participants in the present reported feelings of being left out, ignored, and not supported by the nurses and physicians. They believed that the nurses’ attention was mostly focused

on the recipients and that they were treated with impatience and inattention. The study by Sanner (2005) showed that some of the donors reported feelings of being abandoned, left out, and neglected by the personnel of the ward (18). In this regard, Elciego and Doman (2011) recommended and emphasized that the control, follow-up, and accurate observation by the transplantation team of the donors should be the same as for those of the recipients (17). Although donors in the study by Delanaye (2012) had positive experiences from the received cares in the hospital, most of them experienced a lack of follow-up care after being discharged (19). Some felt neglected by and insignificant to the treatment team, and some even felt that the treatment team has treated them as a tool to end the recipient's treatment. Donors in the study by Lima et al. (2) in 2006 were also dissatisfied with the received medical services during their hospitalization.

Some of the participants in the present study stated that they had not received any educational program for preparation for the surgery or for taking care of themselves after discharge and performing routine follow-up visits to the physician or the nurse from the transplantation team. Lack of sufficient information after donation is one of the disadvantages of the donation process. Therefore, it is necessary for the health personnel to have appropriate understanding of the nature of the donation process and the needs of the donors (6). Focusing on physical, mental, psychological, and interpersonal factors during counseling and educating the donors is essential (19, 20). In the study by Mazaris et al. (21) in 2012, the greatest sources of information for the donors were the transplantation team, journals, and electronic media. Results of another study showed how the lack of knowledge and awareness could affect different aspects of donation (22). The lack of knowledge and awareness might cause the donor to avoid donation. The need for educating the donors is the content of most of the conducted studies (1, 2).

Endless concern was another challenge faced by the relative donors in the present study. The most important concern of the donors after donation was that the recipient's body would reject the kidney (13, 22). In the process of donation, the donors' priority is always attending to the needs of the recipient, and they mostly felt concerned about the results of the transplant and failure in transplant (1). Donors in the study by Lennerling et al. (23) in 2004 were also concerned about the health of and prognosis of donation in the recipient during the entire donation process. Sacrifice, dedication, forgiveness, and self-devotion in donation are some of the features of the donors in the present study. In general, the experience of surgery by the donors has been reported to be somewhat unfamiliar and dissimilar to anything else. Usually, the recipient and the donor would both feel much fear and anxiety during the process of donation. They usually fear death and are anxious about the consequences that might happen after donation. Their fear usually increases at the day of the procedure, and it includes the fear of risking their lives, fear of pain, fear of the unknown, fear of the post-

operative consequences, fear of opioids, fear of the operating room, and fear of being away from the family (24). In a thematic synthesis conducted by Tong et al. (25) in 2012, most donors stated that after the donation, they were particularly concerned about the recipient and the possibility of failure in the function of the donated kidney. Most of the concerns of the donors were regarding postoperative pain, duration of recovery, recipient's health, occupational issues, possible risks, and limitations in the new lifestyle.

The findings of this study showed that relative kidney donors face numerous challenges in the donation process. Focusing on the concerns of donors at the initial consultation and trying to shorten the test duration will be helpful. Nurses can provide more favorable conditions with more support from family donors seeking hospitalization and respect for their rights. Establishment of the Donor Support Association to address the problems and needs of these individuals will be effective in improving the quality of life and addressing their concerns.

CONCLUSION

The present study aimed to discuss some of the challenges faced by relative donors. The duration of testing, not respecting the rights of the donors during the period of hospitalization, and various concerns by the donors were some of the challenges faced during the donation process. According to the results of the present study, the presence of a counselor or a psychologist, especially during the hospitalization period, could be helpful in decreasing the concerns of the donors. Because there are few relative kidney donors in Iran, finding participants for the present study was difficult. In addition, similar to other qualitative studies, the generalizability of the present study is low.

Ethics Committee Approval: Ethics committee approval for this study was received from the research ethics committee of the Tehran University of Medical Sciences.

Informed Consent: All participants gave informed consent for the research, and their anonymity was preserved.

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REFERENCES

1. Ummel D, Achille M, Mekkelholt J. Donors and recipients of living kidney donation: A qualitative metasummary of their experiences. *J Trans* 2011; 21: 1-11. [\[CrossRef\]](#)
2. Lima DX, Petroianu A, Hauter HL. Quality of life and surgical complications of kidney donors in the late post-operative period in Brazil. *Neph Dial Transplant* 2006; 21: 3238-42. [\[CrossRef\]](#)
3. Suzanne C, Smeltzer O. Brunner & Suddarth's Textbook of Medical Surgical Nursing (12th ed.). Philadelphia: Wolters Kluwer/Lippincott Williams & Wilkins, 2014, 642-51.
4. Timmerman L, Laging M, Westerhof GJ, Timman R, Zuidema WC, Beck DK, et al. Mental health among living kidney donors: A prospective comparison with matched controls from the general population. *Am J Transplant* 2015; 15: 508-17. [\[CrossRef\]](#)
5. Mathur AK, Ashby VB, Sands RL, Wolfe RA. Geographic variation in end-stage renal disease incidence and access to deceased donor kidney transplantation. *Am J Transplant* 2010; 10: 1069-80. [\[CrossRef\]](#)
6. Farahani ZB, Esmaeili M, Salsali M, Nayeri N. Living related transplantation: the outcomes of kidney donation in Iran. *Acta Medica Mediterranea* 2016; 32: 1071.
7. Fallahzadeh MK, Jafari L, Roozbeh J. Comparison of health status and quality of life of related versus paid unrelated living kidney donors. *Am J Transplant* 2013; 13: 3210-4. [\[CrossRef\]](#)
8. Zheng XY, Han S, Wang LM, Zhu YH, Zeng L, Zhou MS. Quality of life and psychology after living-related kidney transplantation from donors and recipients in China. *Transplant Proc* 2014; 46: 3426-30. [\[CrossRef\]](#)
9. Santori G, Barocci S, Fontana I, Bertocchi M, Tagliamacco A, Biticchi R, et al. Kidney transplantation from living donors genetically related or unrelated to the recipients: a single-center analysis. *Transplant Proc* 2012; 44: 1892-6. [\[CrossRef\]](#)
10. Garcia MFFM, Andrade LGM, Carvalho MFC. Living kidney donors--a prospective study of quality of life before and after kidney donation. *Clin Transplant* 2013; 27: 9-14. [\[CrossRef\]](#)
11. Vemuru Reddy SK, Guleria S, Okechukwu O, Sagar R, Bhowmik D, Mahajan S. Live related donors in India: Their quality of life using world health organization quality of life brief questionnaire. *Indian J Urol* 2011; 27: 25-9. [\[CrossRef\]](#)
12. Simforoosh N, Soltani MH, Basiri A, Tabibi A, Gooran S, Sharifi SH, et al. Evolution of laparoscopic live donor nephrectomy: A single-center experience with 1510 cases over 14 years. *J Endourol* 2014; 28: 34-9. [\[CrossRef\]](#)
13. Anderson MH, Mathisen L, Oyen O, Wahi A, Hanestad BR. Living donors experiences 1 week after donating a kidney. *Clin Transplant* 2005; 19: 90-6. [\[CrossRef\]](#)
14. Streubert HJ, Carpenter DR. *Qualitative Research in Nursing*. Philadelphia: Lippincott, Williams & Wilkins, 2011.
15. Holloway I, Wheeler S. *Qualitative Research for Nurses*. Blackwell Science Publishing, 2010.
16. Stothers L, Gourlay WA, Liu L. Attitudes and predictive factors for live kidney donation: A comparison of live kidney donors versus non-donors. *Kidney Int* 2005; 67: 1105-11. [\[CrossRef\]](#)
17. Elcioglu O, Duman S. Concept of the voluntariness in kidney transplantation from the position of donors and recipients. *Glob Bioeth - Perspect Hum Surviv* 2011; 1: 31-7. [\[CrossRef\]](#)
18. Sanner MA. The donation process of living kidney donors. *Nephrol Dial Transplant* 2005; 20: 1707-13. [\[CrossRef\]](#)
19. Delanaye P, Weekers L, Dubois BE, Cavalier E, Detry O, Squifflet JP, et al. Outcome of the living kidney donor. *Nephrol Dial Transplant* 2011; 27: 41-50. [\[CrossRef\]](#)
20. Gill P. Stressors and coping mechanisms in live-related renal transplantation. *J Clin Nurs* 2012; 21: 1622-31. [\[CrossRef\]](#)
21. Mazaris EM, Warrens AN, Smith G, Tekkis P, Papalois VE. Live kidney donation: attitudes towards donor approach, motives and factors promoting donation. *Nephrol Dial Transplant* 2012; 27: 2517-25. [\[CrossRef\]](#)
22. Siegel JT, O'Brien EK, Alvaro EM, Poulsen JA. Barriers to living donation among low-resource Hispanics. *Qual Health Res* 2014; 24: 1360-7. [\[CrossRef\]](#)
23. Lennerling A, Forsberg A, Meyer K, Nyberg G. Motives for becoming a living kidney donor. *Nephrol Dial Transplant* 2004; 19(6):1600-5. [\[CrossRef\]](#)
24. Ghahramani N, Karparvar Z, Ghahramani M, Shadrou S. International survey of nephrologists' perceptions and attitudes about rewards and compensations for kidney donation. *Nephrol Dial Transplant* 2013; 28: 1610-21. [\[CrossRef\]](#)
25. Tong A, Chapman JR, Wong G, Kanellis J, McCarthy G, Craig JC. The motivations and experiences of living kidney donors: A thematic synthesis. *Am J Kid Dis* 2012; 60: 15-26. [\[CrossRef\]](#)