

Research on the Psychological Problems of the Living Kidney Donors Who Need Support from the Professional Transplant Team

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Abstract

The purpose of this study is to identify the psychological problems of the living kidney donors (LKD) before and after nephrectomy. The research was a retrospective study of 270 living kidney donors (100 men and 170 women) who donated their kidney from July 2009 to March 2011. Data was collected from the electronic medical and nursing records on age, sex, relation to the recipient, the motifs to donation, anxiety, and psychological problems or events related to donation. Data related to anxieties and worries was also collected by means of a self-administered questionnaire survey.

As results, there were 7 donors (3 wives, 2 children, a parent, and a husband) from 40s to 60s who had psychological problems or events before admission and/or after nephrectomy. The number of hospitalization was between 6 to 14 days, whereas all donors' average was 7.4 (SD=2.6) days. Two donors had problems both before and after donation. There were 4 donors who had psychological problems before admission, and 3 out of 4 donors' motives to donation were unknown. There were 3 donors who had psychological problems or complaints after donation, such as anorexia or toward to noncompliance of the recipient who had received the donor's kidney.

In conclusion, there was small number of donor who had psychological problem and felt anxiety; however, he or she needs support from the physician of psychosomatic internal medicine. And also, the nurses who take care of the donors have to collaborate with other staff, such as outpatient clinic, ward, operation room, and intensive care unit. The recipient transplant coordinators who take care of both recipients and living donors also professional nurse for the transplant team.

1. Introduction

The end stage of chronic renal disease need hemodialysis, one of renal replacement therapies known as an artificial kidney, which takes 3 times per week and 4 to 5 hours at a treatment. Such hemodialysis patients want to receive kidney transplantation. Kidney transplantations rely on two types of donors: cadaveric or living one. Because of the shortage of organ donation from the cadaveric donors in Japan, family members are willing or reluctant to donate their kidneys.

One of two kidneys is able to donate; however, the donor's renal function will be half, as well as the donor's quality of life (QOL) will be down. The kidney donation from a healthy person has to be safe and not to be forced.

The Japan Society for Transplantation ^(1, 2) restricts those who can become living kidney donors (hereinafter LKD) to consanguineal relatives within

6 degrees of separation of the recipient and affinal relatives within 3 degrees of separation. This restriction has been laid down to prevent paid donations, to ensure the voluntary character of LKD, and so that pre-donation physical and psychological check-ups and post-donation follow-ups can be fully implemented.

With regard to psychological problems among LKD, Haruki ⁽³⁾ indicates that postoperative cases of depression may occur irrespective of the success of living-donor kidney transplantation. Normally, there are problems with the reduction in QOL in healthy individuals as a result of kidney donation.

The purpose of this study is to identify the psychological problems of the living kidney donors before and after nephrectomy.

2. Review of Related Literature

A database search was conducted using the

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Japan Medical Abstracts Society (Ichushi WEB), CiNii, Medical Online, and PubMed to identify literature related to LKD. It was found that while few original papers had been published in Japan, there were a large number of conference proceedings. It was also found that a significant amount of literature by Japanese researchers on the topic of LKD had been published overseas.

Okamoto, *et al.* ⁽⁴⁾ stated that only 3 out of 601 living kidney donors had the post-operative complications, and the mortality rate was the same as the healthy people.

Wiedebusch, *et al.* ⁽⁵⁾ found that 104 donors recovered the state of health within 6 months after operation and that psychological health did not change; however, 25% of donors had anxiety and depression.

Langenbach, *et al.* ⁽⁶⁾ investigated that 11 donors who donated their kidney from 2 to 3 years after had difficulty of adjustment to new life, hypochondria, physical uncomfotableness, and fear of rejection which was the immunological reactions of the recipient toward the donated kidney.

3. Subjects

One hundred men and 170 women who donated their kidneys from July 2009 to March 2011 participated in this study.

4. Data Collection Methods

Data collection was from April 2011 to March 2012. Data was collected from the electronic medical and nursing records as follows: age, sex, relationship to the recipient, number of hospitalization days, and psychological problems.

Data related to anxieties and worries was also collected by means of a self-administered questionnaire survey.

5. Ethical Considerations

Consent for the study was obtained using documentation to explain the purpose, significance, methods, and ethical considerations of the study to the chief professor of the partner research facility. Then, with reference to information on living-donor kidney transplants that had been performed in the

past at the same facility, permission to consult electronic medical records for research purposes was applied for and obtained, whereupon researchers received an ID and password. Anonymity was ensured by withholding names and ages from the research subject data.

For the questionnaire survey, an explanatory note and a self-addressed envelope were enclosed with a copy of the questionnaire, with subjects having been asked to return the questionnaire only in the case that they agreed to participate in the study. Also, questionnaire sheets were unsigned, providing assurance of anonymity.

The data obtained for use in this study was saved to a USB memory stick using double-coded anonymity and secured to be only available for browsing by researchers. The USB drive was then stored in a cabinet that researchers kept under lock and key.

Permission from the ethical committees in order to gathering data from the electronic medical and nursing records and doing for this study was obtained.

6. Results

A total of 270 research subjects was included in the study, consisting of 100 men and 170 women. Of these, questionnaires were collected from 195 individuals (a collection rate of 72.2%).

The mean age for all participants was 56.9 years (with a SD of 9.9 years), with a break up of 56.0 (SD = 10.4) for men and 57.4 (SD = 9.7) for women. Broken down by age, the subjects included 1 woman in her twenties, 17 people in their thirties (8 men and 9 women), 46 people in their forties (20 men and 26 women), 79 people in their fifties (27 men and 52 women), 108 people in their sixties (40 men and 68 women), and 19 people in their seventies (5 men and 14 women). See Figure 1.

The relation to the recipient was 78 mothers, 72 wives, 48 husbands, 34 fathers, 15 sisters, 13 brothers, 8 children and others (a cousin and an aunt). See Table 1.

There were 7 donors who had psychological problems before admission and/or after donation in the nursing records and questionnaires (Table 2). The characteristics of these donors were 5 females and 2 men from 40s to 60s. Their recipients who

received donor's kidney were spouses, children, and parent. The number of days in hospital stay was from 6 to 14 days, whereas the average for all donors' hospital days was 7.4 (SD=2.6) days. See Table 2.

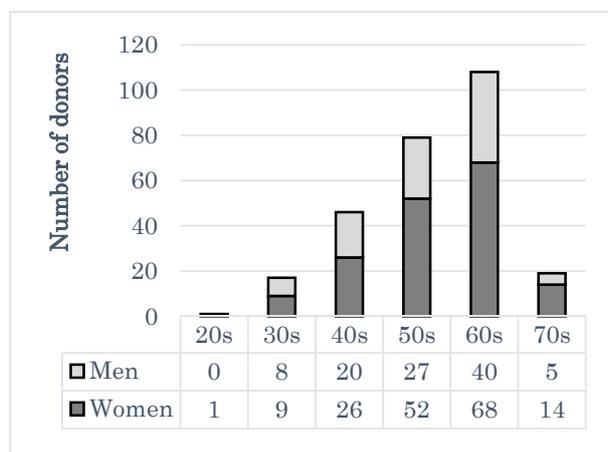


Fig. 1. Number of donors by gender and age

Table 1

Relationship to the recipients in this study		
	Frequency	Percent (%)
Mothers	78	29
Wives	72	27
Husbands	48	18
Fathers	34	13
Sisters	15	6
Brothers	13	5
Children	8	3
Others	2	1
Total	270	100

Each case was shown as following.

Donor A (a woman in her fifties) donated a kidney to her husband. The background and motivation behind the decision to donate was unclear, and the woman was taking oral tranquilizers for a panic disorder. A nurse in the outpatient clinic wrote that the person asked on the telephone what would be needed for admission and how she should take a laxative. While she was discharged from hospital without any particular problems during her stay, she became distressed and caused a commotion when her husband was also discharged from hospital

earlier than planned. She visited to the internal medicine office when her gastrointestinal condition worsened and her mood became depressed.

Donor B (a woman in her fifties) donated a kidney to her husband. Although her motivation for donation was not mentioned during her outpatient visits, she spoke at length and called the nurse after returning home, repeating the same conversation. She grew fearful upon listening to the informed consent on the day before surgery and said that it would have been better if she had not heard the explanation of the nephrectomy. She panicked and grew fidgety after the extubation once the surgery was complete.

Donor C (a woman in her sixties) donated a kidney to her child. Her motivation for donating the kidney stemmed from a phone conversation in which her child asked her for the operation. She said before admission that "I felt pressure when I might be a donor, and I had a trouble on my job, then I caught up in a panic."

Donor D (a man in his sixties) donated a kidney to his child. A physician in the internal medicine office sent a referral to the recipient transplant coordinator with regard to this case, noting that while there were no problems in terms of the donor's indication of the voluntary nature of his decisions, there was an element of an atmosphere of pressure on the part of the entire family imploring the donor to do everything he could to support the recipient. The donor gave the impression of isolation. There was a desire that the donor's sentiments should be conveyed to the recipient. In a second interview, the donor was observed to have gained weight, occasioning criticism from his family.

Among the four cases listed above, two exhibited psychological problems before and after the time of the donation.

Next, one donor was observed to exhibit psychological problems after the donation.

Donor E (a man in his fifties) donated a kidney to his wife. After the donation, he lost his appetite, leading to weight loss necessitating infusion treatment. He was hospitalized for a period of 14 days, longer compared to the hospitalization period of other donors. He visited to the internal medicine office and became better after being asked to listen to doctors' conversation.

Furthermore, the following two cases involve donors who expressed dissatisfaction with the recipient after the surgery.

Donor F (a woman in her sixties) donated a kidney to her husband. While the topic of the kidney transplant was broached by her husband, she was initially reluctant. She had once been saved from a major illness herself, and as she was getting on in years, she decided to make the donation. However, while her husband's health improved after the donation, she expressed dissatisfaction with him for not honoring his promises to give up smoking and

drinking alcohol. She felt that her sacrifice had been a waste.

Donor G (a woman in her forties) donated a kidney to a parent. Prior to the donation, there had been a feeling of mutual aid between parent and child, and there had been no problems in terms of the donation. After the donation, when her parent seemed to have forgotten about the suffering caused by life on dialysis, the daughter asked the physician to occasionally caution her parent on matters of diet and the like. See Table 2.

Table 2
Demographic characteristics of case

Case	Sex	Age	Recipient	Number of hospitalization days	Time of event at donation
A	F	50s	husband	7	Before & after
B	F	50s	husband	6	Before & after
C	F	60s	child	6	before
D	M	60s	child	7	before
E	M	50s	wife	14	after
F	F	60s	husband	7	after
G	F	40s	parent	8	after

7. Discussion

Cases Where Problems Were Evident Before Donation

The results of this study revealed psychological problems in terms of the panic that arose before donation in cases of people who were surprised at the unexpectedness when asked to donate an organ by the presumed recipient. Haruki ⁽⁷⁾ represents the decision stage of the living kidney donor candidate as "the unusual event of a scalpel being inserted into a healthy body." Sources of psychological problems caused prior to donation by LKD may possibly have been the surprise, fear, or sense of denial prior to the donation.

Next, in cases where criticism was copped from the family prior to donation, receiving a follow-up by a psychiatrist in the internal medicine office seemed to be able to ease the psychological burden of LKD at least in part. Haruki ⁽⁷⁾ has pointed out that intra-

family tensions can be exacerbated when a potential donor is subject to environmental pressure to consent to be a living kidney donor, making it impossible to refuse organ donation. This suggests the need for nurses with the job profile of providing emotional support for the feelings of LKD. In university hospitals and other transplant centers, recipient transplant coordinators who specialize in living-donor transplants are needed who will carry out support not only for recipients but also for donors. In this study, a case was observed in which a diagnostic physician sent a note to a nurse indicating a desire "to convey LKD's feelings to the recipient and other family members in order that LKD not be isolated." In this case, it is speculated that the absence of post-donation psychological problems was due to the collaboration between medical professionals.

Cases Where the Intention to Donate Was Not Seen

To Be Voluntary

In transplants requiring a living donor, such as kidney transplants or liver transplants, making the decision to determine who in the family will become a donor can be a difficult matter. This is because surgery is carried out on a healthy body as well as due to the fact that, on top of the risks of general anesthesia, approximately half the functionality of the donated organ will be lost. In addition to these physical effects, there are also effects on the psychological aspects of donation, such as the fear of surgery and general anesthesia and anxieties about pain after the operation. With regard to the social aspects, there are various questions that need to be addressed as well, including how many days someone must take off work, the length of time it will take to be able to reintegrate into society, and the person who will do the housework and look after the patient and the family. In other words, when it can be expected that two members of the same family will be hospitalized, these difficult conditions are easy to imagine.

In this way, various intra-familial conflicts become apparent when choosing a donor candidate, and becoming a donor candidate represents a unique experience. Takada ⁽⁸⁾ reports that for LKD, the experience of donating an organ may entail an active belief that “I’m the only one who can help” or a reluctance to recognize the same but that in either case, uncertainty persisted up until immediately before the donation. In the cases detailed in this study, cases in which the intention to donate was unclear entailed a strong sense of denial about the donation until the last minute, suggesting the possibility of the appearance of some psychological problems ⁽⁹⁾.

Cases Where the Post-Donation Situation Was Not As Expected

In the process of donating a kidney, even where there are no problems in the relationship between the recipient and other family members, cases were observed in which psychological states became unstable after donation. Moreover, cases were observed in which the recipient’s behavior provoked a sense of dissatisfaction. This is considered to be the complexity of medical transplantation. This seems to be due to the fact that, since this type of

medicine involves the revival of one body through the provision of an organ from another individual, whether living or deceased, the sense of gratitude to the donor when the transplant surgery is successful tends to gradually fade after the organ donation.

Next, some LKD expressed anxiety and worry about the neglect of health by the kidney transplant patient. In cases in which the living kidney donor lived together with the kidney transplant patient, the former was in a position to have a clear idea of the latter’s everyday behavior. It has already been pointed out elsewhere that there are cases in which, after a donation, LKD can feel that “since I donated a kidney, I want [the recipient] to exercise more careful self-management,” possibly giving rise to mental health problems among family members ⁽¹⁰⁾. The long-term functioning of the donated kidney is something desired by all involved in the kidney transplantation, including the donor, and for kidney transplant recipients to be able to exercise self-management is a necessary condition for adaptation to the transplant. While there are many aspects of self-management that are demanded of kidney transplant recipients, the most important of these are taking immunosuppressive agents to prevent rejection of the organ and to take part in outpatient check-ups in order to ensure early detection of any rejection or complications. While early detection of rejection is also possible through symptom awareness and self-management, the vast majority of cases are discovered and confirmed during outpatient check-ups or through hospitalization ⁽¹¹⁾. Among the reasons for the cancellation of the kidney transplants described above are chronic rejection due to stopping a course of immunosuppressive therapy, which includes simply forgetting to take the prescribed medication. Kosaka et al. have pointed out that after transplant surgery, as time passes, some recipients become more likely to neglect outpatient check-ups and medication management ⁽¹²⁾. Providing guidance to kidney transplant recipients who are neglectful of their health in this way is an important role of physicians.

Moreover, for women who became LKD, housework is a burden after they are discharged from hospital until such time that they recover to

their pre-donation physical condition, and there were also cases of those who felt trapped in psychological terms. From this fact, as well, it is important that family members apart from the kidney transplant recipient also be present in order to support LKD in their role within the family and to ensure that LKD get sufficient rest after the organ donation.

While the possibility that the notes made in the nursing and diagnostic records was only partial cannot be discarded, this was a limitation of the data collection methods used for this study. At the partner research facility, where psychological problems were apparent in LKD before or after donation, nurses would make referrals to physicians in the psychosomatic or psychiatric ward through a recipient transplant coordinator, who would consult to enable the LKD to express their psychological burden. There is a need for such cases to be annotated in diagnostic and nursing records.

8. Conclusion

(1) There were 7 donors out of 270 who had psychological problems or events before admission and/or after nephrectomy.

(2) They were 2 men and 5 women from 40s to 60s by age and the relation to the recipient was 3 wives, 2 children, a parent, and a husband.

(3) One man and 3 women revealed psychological problems before donation because they did not prepared for being a donor, were not voluntary, or there was existing intra-family tensions.

(4) One man and 4 women revealed psychological problems or events after donation. The reasons why psychological state became unstable after donation were lack of communication with the medical staff and dissatisfaction with recipients' noncompliance.

(5) The small number of donors in this study had psychological problems; however, they would need support from the nurses, especially transplant coordinator, and physicians in the psychosomatic or psychiatric ward.

Note

This study represents a modified and expanded version of a portion of my doctoral thesis for the Health Sciences of Mind and Body Program in the

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References

- (1) The Japan Society for Transplantation, "*Nihon ishoku gakkai rinri shishin* [JST Ethical Guidelines]", 2015, p. 2. URL: http://www.asas.or.jp/jst/news/doc/info_20151030_1.pdf [Accessed 2016/2/20]
- (2) The Japan Society for Transplantation, "*Seitai jin ishoku no donā gaidorain* [Donor Guidelines for Living-Donor Kidney Transplantation]", p.2, <http://www.asas.or.jp/jst/pdf/manual/008.pdf>
- (3) Haruki, K. "Seitai jin ishoku ni kanren suru donā, reshipiento no seishin igaku-teki mondai [Japanese Psychiatric Problems with Renal Transplants from Living Relatives]". *Rinshō tōseki* [Clinical Dialysis] 22 (10), 1349-1358. 2006.
- (4) Okamoto, M., Akioka, K., & Nobori, S., *et al.*: "Short- and Long-Term Donor Outcomes After Kidney Donation: Analysis of 601 Cases Over a 35-Year Period at Japanese Single Center. *Transplantation*, 87(3), 419-423. 2009.
- (5) Wiedebusch, S., Reiermann, S., & Steinke, C. *et al.*: Quality of Life, Coping, and Mental Health Status after Living Kidney Donation. *Transplant Proceedings*, 41(5), 1483-1488. 2009.
- (6) Langenbach, M., Stippel, A., & Stippel D.: Kidney Donors' Quality of Life and Subjective Evaluation at 2 Years after Donation, *Transplant Proceedings*, 41, 2512-2414. 2009.
- (7) Kazushige, H.: Zōki ishoku ni kanren suru seishin igaku-teki mondai - Nihon ni okeru

- seitai jin ishoku no keiken o chūshin ni: Dai-2-bu: Donā no seishin igaku-teki mondai [Psychiatric Problems in Organ Transplantations: Examples on the Kidney Transplants from Living Relatives in Japan (Part 2: Psychiatric Problems among Donors)]. *Ishoku* [Transplantation], 40(3), 264-272. 2005.
- (8) Takada, Y.: Seitai jin ishoku donā no jin teikyō no taiken [Experiences of Kidney Donation in Living Kidney Donors]. *Nihon kango-ka gakkai shi* [Journal of Japan Academy of Nursing Science]. 29(5), 24-33. 2009.
- (9) Haruki, K.: Seitai jin ishoku ni okeru donā kōho-sha no jin teikyō no jihatsu-sei o tashikameru seishin igaku-teki mensetsu no yōten: Rinshō keiken kara ieru koto [Key Points from Psychiatric Interviews to Verify the Voluntary Character of Kidney Donation in Living Renal Transplantation]. *Ishoku* [Transplantation], 42(4), 335-341. 2007.
- (10) Haruki, K.: Zōki ishoku ni kanren suru seishin igaku-teki mondai - Nihon ni okeru seitai jin ishoku no keiken o chūshin ni: Dai-2-bu: Donā no seishin igaku-teki mondai [Psychiatric Problems in Organ Transplantations: Examples on the Kidney Transplants from Living Relatives in Japan (Part 2: Psychiatric Problems among Donors)]. *Ishoku* [Transplantation], 40(3), 264-272. 2005.
- (11) Yokoyama, K. & Koike, J.: Banff' 05 ni motodzuku ishoku jin soshiki shindan no saikentō: Mansei kōtai kanren-gata kyozetsu han'nō no shindan to kongo no tenbō [Reexamination of the Histology of the Transplanted Kidney by the Banff' 05 Criteria: Diagnosis of Chronic Antibody-Mediated Rejection and Future Prospects]. *Tōkyō ika daigaku zasshi* [The Journal of Tokyo Medical University], 67(3), 291-298, 2009.
- (12) Kosaka, S., Tanaka, M., Sakai, T., *et al.*: Jin ishoku-go reshipiento no jiko kanri kōdō no jittai to keika kikan to no kankei [Survey of self-management in kidney transplant recipients and its association with their post-transplantation period]. *Ishoku* [Transplantation], 47(1), 60-66. 2012.