J Exp Clin Med 2012;4(2):125–129

Contents lists available at SciVerse ScienceDirect

Journal of Experimental and Clinical Medicine

journal homepage: http://www.jecm-online.com

ORIGINAL ARTICLE

Donating a Kidney in Taiwan: A Study of 90 Relative Living Donors

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ARTICLE INFO

Article history:
Received: Dec 9, 2011
Revised: Jan 18, 2012
Accepted: Jan 18, 2012

KEY WORDS:
decision-making process;
kidney transplantation;
relative living donors

Background: Some specific findings from the psychiatric evaluation of 90 living relative donors and the recipients before kidney transplantation in Taiwan during the mid 1970s to the early 1980s are reported. We highlight the attitude of the parental donors, their decision-making process, and the emotional turmoil at the time of family crisis in the context of cultural background.
Method: As a required routine examination in kidney transplantation, we interviewed 90 prospective donors referred by the kidney transplantation team before and after the surgery. The interview was conducted in a semistructured and open-ended fashion.
Results: Unless medically unfit or strongly opposed by the other family members, a great majority of the parents, particularly the mothers, first volunteered to donate a kidney. Significantly, the sons had more opportunities to receive a kidney from either parent than daughters regardless of marital status. Although the decision-making for donation by the parents was instantaneous and occurred in the early stage, the rates of giving-up decision for donation was significantly lower than that of donation by siblings or other relatives. They were not or did not want to be well informed about kidney transplantation; they even gave many reasons to justify their decision to donate a kidney and to rationalize their anxiety over the results of the transplantation surgery. The process in decision-making and the donor selection often provoked the underlying intrafamily conflict, and led to giving up transplantation surgery. Denial, compensation, rationalization, and displacement were the commonly observed defense mechanisms against anxiety, guilt feelings, or hostility. Anxiety and depression were common among those donors.
Conclusion: The importance of psychiatric evaluation before transplantation surgery and the specific need for long-term care for the donors after operation are emphasized.
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1. Introduction

That kidney transplantation with hemodialysis as an alternative is the best treatment for patients with terminal renal failure has been a well-documented evidence during the past several decades. Although transplantations from cadaveric grafts have increased in recent years, earlier studies have unanimously shown the superior results of transplantation from the grafts of blood-related donors to cadaveric grafts.[1] The transplantation from the graft of a living donor, however, requires careful attention to the health, and welfare, and quality of life of the donors. The selection process and decision-making for donation are critical life events for both donors and recipients, and may cause emotional conflict among them and other family members. The graft recipients usually have to undergo long-term treatments with immunosuppressive agents and medical care to prevent various medical complications post-operatively. The personality and mental functions of recipients are important factors that influence their compliance with all those therapies. Therefore, the psychiatric evaluation of donors, recipients, and other key family members before and after surgery has been regarded as an indispensable part of the required procedures in kidney transplantation.[2]

Kidney transplantation for terminal renal failure in Taiwan started in 1968 at the National Taiwan University Hospital (NTUH). Beginning in 1974, in accordance with the increase of cases, psychiatric evaluation has formally become a part of routine examinations in kidney transplantation procedures. From 1974 to early 1980s, the authors had had opportunities to carry out psychiatric evaluation on donors and recipients before and after the

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doi:10.1016/j.jecm.2012.01.001

surgery. All grafts were from blood-related living donors. Those experiences have enhanced our understanding of human behaviors during serious life crises, specifically among the Taiwanese.

This paper reports several specific findings on donors, recipients, and their interactions with family members in psychiatric evaluation before and after transplantation surgery at the NTUH.

2. Methods

Altogether, 90 prospective relative donors referred by the kidney transplantation team at the NTUH were studied. They were all ethnic Chinese, consisting of 84 native Taiwanese and 6 overseas Chinese from Southeast Asian countries. There were 34 males and 56 females, with age ranging from 28 to 71 years. The average age for parental donors was 55.7 years, and that for sibling and cousin donors 39.2 years. They were interviewed at least once, but over half of them were interviewed twice or even more pre- or postoperatively.

Aiming at minimizing the defense and maximizing free association of the interviewees, the interview consisted of a mixture of semistructural and open-ended approach, to understand the personal and socioeconomic background, brief history of development and adjustment, physical and mental health, treatment history, if any, personality trait, history of surgery, therapeutic compliance, and the coping strategies of donors at the time of the health crisis. Special attention was paid to understanding the attitude of prospective donors and their family members toward kidney transplantation, motivation for donation, and the psychodynamics in the process of donor selection. Each interview session lasted 1—1.5 hours. The key family members were interviewed if indicated. The prospective recipients were also interviewed at least once before and after surgery in a more flexible manner depending on their physical condition.

3. Results

3.1. Attitude of the family members toward kidney transplantation

When kidney transplantation was first performed at the NTUH, the attitude of the family members toward kidney transplantation was generally skeptical, and they were hesitant to donate. Out of 29 patients who received the kidney transplantation procedure during the mid 1970s, 13 patients had discharged themselves from the hospital when the kidney transplantation was first suggested by nephrologists. They had tried various alternative medicine or even indigenous healing methods until they needed urgently to return to their nephrologists because of their worsening general physical condition.[3] In the late 1970s, after the increase in the number of kidney transplantations and the impact of the news media, the attitude of families of patients toward kidney transplantation became more receptive. Once the family members, particularly the parents, had decided to donate a graft, they felt released from long-standing suffering. They would even directly refer themselves to the surgeons at the NTUH, and requested an earlier operation without psychiatric evaluation. They were afraid that the result of the preoperative psychiatric evaluation might lead to disclosure of something that could interfere with the operation.

The reasons for deciding on a kidney transplantation often included: “dialysis is only a symptomatic release, it is not a radical treatment toward healing, and we cannot afford long-term dialysis,” or “kidney transplantation is a radical treatment, so even with half of opportunities, it is worthwhile trying.” The decision-making process for kidney transplantation often provoked underlying emotional conflicts between the family members, and the decision of the parents to donate a graft was often to compensate for guilt feelings toward the recipients. A 66-year-old male, a retired army officer, volunteered immediately to donate a kidney to his 21-year-old daughter when the kidney transplantation was suggested by the nephrologist. During the interview, he looked depressed and dysphoric with stiff facial appearance, generalized muscle rigidity, and fine tremors, indicating the symptoms of Parkinson’s disease and depression. But he denied all the symptoms. The interview later with his wife revealed that a long-standing emotional conflict had existed in the family. The prospective recipient was the daughter, the eldest of the three children of the family. The second child was the only son who died of renal disease at the age of 10 years. The youngest was a 16-year-old girl who was a mentally retarded. Since the death of their only son, the wife had persistently blamed her husband, the prospective donor, for having neglected the care of the son. She cursed the prospective recipient as “the money-sucker of the family.” The wife had, therefore, opposed strongly against the kidney transplantation by donation from any family members. Thus, the husband did not dare to inform his wife of his decision to donate a kidney until the last minutes before his hospitalization for medical examination. The wife was furious and openly rejected the husband’s decision. After seeking help from indigenous healers and consultation with the relatives and friends, the wife finally and reluctantly agreed with her husband’s decision. The couple was apparently in emotional turmoil during the decision-making process. The wife was also in depressive state, and the couple needed psychiatric treatment before surgery.

3.2. Donor selection process

The majority of donors belonged to voluntary decision-making. Only when they failed to donate by any reasons, did they chose another candidate from family members. There was no single case of the so-called medical-selection system as described elsewhere.[4] As shown in Table 1, 70 out of 90 prospective donors were, primarily the parents. They volunteered to donate a graft in the early stage, and even rejected donations by other family members. There were six exceptional cases whose donations were based primarily on the request of the recipients. Out of 70 primary parental donors, seven cases were found to be medically unfit, and had to choose donors from the siblings of the recipients. There were 10 cases of donors who were selected primarily through a family conference. There were only three cases of sibling donors who primarily volunteered from the beginning, and accepted by the parents. There was a case of a donation volunteered by the mother, but was rejected by the recipient. This patient eventually rejected the kidney transplantation throughout the whole treatment course.

3.3. Donor—recipient relationship: who donated to whom?

As shown in Table 2, out of the 90 prospective donors interviewed, 76 (84.4%) were parental donations, 13 were intersibling donations, and one intercousin donation (15.6%). Out of 76 prospective

Table 1 Donor selection process

	N
Primarily volunteered by either of the parents with rejection of other family members to donate	63
Primarily volunteered by either of the parents, but had to seek for donation from siblings due to medical reasons	7
Selection primarily through family conference	10
Parental donation primarily on the request of recipients	6
Primarily volunteered by siblings, and accepted by parents	3
Primarily volunteered by mother, but rejected by recipient	1
Total	**90**

Table 2 Donor–recipient relationship: who donates to whom?

	N		(%)
Parental donations			
Fathers to sons	19	60	(66.7)
Mothers to sons	41		
Fathers to daughters	6	16	(17.8)
Mothers to daughters	10		
Subtotal		**76**	**(84.4)**
Sibling/cousin donations			
Elder to younger brothers		6	
Younger to elder brothers		2	
Elder sisters to younger brothers		2	
Younger sisters to elder brothers		2	
Younger to elder sister		1	
Cousin brother to elder cousin sister		1	
Subtotal		**14**	**(15.6)**

parental donors, 51 were maternal and 25 were paternal donors. The opportunity for sons to receive donations from either parent was significantly higher than daughters regardless of marital status (Table 3). There was, however, no difference in the opportunity for either parent donate to sons or daughters. Out of 14 intersibling and intercousin donations, the rate of giving-up donations in the final stage was as high as 57.1% (Table 4). This was significantly higher than that of parental donations (15.8%) ($\chi^2 = 9.44$, $p < 0.01$).

It is noteworthy that while "medically unfit" was the major reason for parents to give up donations, opposition by spouses or other siblings or interpersonal conflicts between family members were the major reasons for giving up donations among intersiblings. Maternal donors gave many reasons to justify their decision for donation and to reject donation from other family members. "I am the mother of the recipient, I am best fit," or "I am going to give him (her) the second birth," or "father has to work to support family, but I do not have to," or "I am old, the remaining life is short." It is natural and worthwhile to donate my kidney to save my child who is still so young," or "doctor said I can live well with one kidney," were the most frequent comments made by maternal donors during the interview. It was also remarkable that although the decision-making for donation was made in the early stage and instantaneous, they seldom changed their mind unless they were found to be medically unfit, or on rare occasions, the decision was strongly opposed by other family members. This showed that the decision for donation by the parents was significantly much firmer than that of intersibling and intercousin donations.

3.4. The myth of the informed consent

"Informed consent" means that the patient's consent to undergo any kind of medical procedures must be voluntary and based on full information about the diagnosis, etiology, severity of symptoms, clinical course and prognosis, proposed examination or treatment, risks and effects of treatments. The patient should also be given all information regarding any other treatments and its outcome, and the information regarding the possible risks if the treatment under consideration is not carried out in time. This is not only a matter of medical ethics, but also a legal requirement in Taiwan.[5] Furthermore, the process involved in giving informed consent provides opportunities to establish good doctor–patient relationship through: (1) forming a closer bond between both parties, (2) imparting relevant medical knowledge, and (3) observing the patient's competency of understanding and emotional reactions.[6] In kidney transplantation, consent for the surgery and the selection of donors are based on full information about the surgery from the referring nephrologists and the surgeons in charge.

Table 3 Donor–recipient relationship among the 76 prospective parental donors

Recipients	Donors		
	Mother	Father	Total
Sons	41	19	60
Daughters	10	6	16
Total	**51**	**25**	**76**

Donations: mothers > fathers; $\chi^2 = 8.89$, $p < 0.01$.
Recipients: sons > daughters; $\chi^2 = 25.47$, $p < 0.01$.
Fathers/Mothers vs. sons/daughters; $\chi^2 = 0.02$.

Table 4 The rate of giving-up donation among the 90 prospective donors

Donors	Number operated	Number gave up	(%)	Total
Parents	64	12	(15.8)	76
Siblings/cousins	6	8	(57.1)	14
Total	**70**	**20**	**(22.2)**	**90**

$\chi^2 = 9.44$, $p < 0.01$.

In the majority of the prospective parental donors, this was, however, not the case. Their knowledge regarding the various aspects of kidney transplantation was quite limited, and they were actually not as eager to be informed as one would expect. They appeared to be even aloof to this matter, a phenomenon that is particularly predominant among this group of donors. They would even give various excuses for not being well informed regarding the kidney transplantation. They would say that "doctors at the NTUH are the best of the country, and I trust them," or "kidney transplantation is the only radical treatment for my son (or daughter)," or "many parents had been operated, why should I hesitate," or "doctor said I could live OK with one kidney," or "should there be any health problems after operation, I will be well-served by other family members. Why should I worry?" They often even requested the interviewer not to inquire too much, and to just support their decision to go through with the operation without delay. They often denied fear or anxiety, and appeared to be optimistic about the outcome of the surgery. Thus, in such a major surgery, which was critically important to the life and health of both recipients and donors, the issue of informed consent was actually the myth. This peculiar psychological phenomenon, called "cognitive dissonance," has also been observed in earlier studies in the United States.[7] Theoretically, one's decision to donate a kidney to save a life must be based on the donor's competent cognitive functions to understand the full information given by the nephrologist and transplant surgeon. When the donors are the parents, this basic principle in decision-making for donation did not seem to work right. Their cognitive functions were easily obscured by the overwhelming emotions between the donor, the recipient, and the other family members. These psychological phenomena are not specific to the decision-making for donation of a kidney by living relative donors, but are also frequently observed in any life-threatening illness when one has to make a decision to receive any specific treatment. These specific psychological mechanisms are not unique to the Taiwanese and Americans, but are perhaps also shared by all human beings regardless of culture.

3.5. Interactions between donors and recipients

When the prospective donors were the parents, the recipients appeared to find the decision easier to accept compared to their sibling donors. Anxiety and guilt feelings toward parents were often rationalized as, "I accept the donation because this has been what doctor suggested," or "my mother is going to give me the second birth." The sense of guilt was often compensated for by open comments such as, "I will return my gratitude by showing more filial pieties to my parents after operation." Some parental

donors did not disclose their decision to give a graft to the recipient until the last moment before hospitalization for medical examinations, because they were afraid of the recipients' adverse emotional reaction. They even requested the medical staff not to tell the recipients about their decision before the final results of the examination would show "medically fit."

On rare occasions, the recipients showed drastic emotional reactions when they were informed that the donors were their parents. A young male prospective recipient became quite agitated with severe depressive mood, and requested immediate discharge from the hospital after learning that the donor was his widowed mother. A young female college graduate was agitated with anger that she was "cheated" by her mother, who hid the information from her, after she learned that the prospective donor was her father a few days before the operation. She became openly hostile to her mother, and insisted that the mother had always had a controlling attitude toward the recipient and her father since her childhood.

When the prospective donors were married siblings, or when the recipients were married daughters of the family, the psychodynamics in the family or between the in-law families would be usually not as simple as in the cases of parents-to-sons donations. They were usually affected by the attitude of the spouses or the parents-in-law of the donors and recipients. Often, anxiety, anger, hostility, and guilt feelings between the donors and recipients were displaced to other persons, such as the ward staff or transplantation team members or even psychiatric interviewers. A 56-year-old mother decided to be a donor for her 30-year-old married daughter on the condition that the son-in-law was responsible for the whole medical expenses and liabilities that may be caused by the surgery. During the routine medical examination, the mother was openly demanding and hostile with many complaints about the ward staff. She was critical of the psychiatric examination, describing it as just a waste of time. She requested the surgery to be carried out as soon as possible. She complained of pain during radiological examination of her kidneys. When she was informed about the need for a second blood sampling for liver functions, she became furious and immediately discharged herself from the hospital. The daughter became depressed and had suicidal ideas. She also became rebellious and antagonistic to the ward staff. She was so angry that also discharged herself from the hospital right away when minor questions about the medical fees that were not covered by the health insurance were raised.

4. Discussion

4.1. Cultural aspects of the attitude of relative living donors

As shown in Table 1, majority of primary donors (79%) who volunteered to donate from the beginning were the parents as compared to only 3% (3 cases) for siblings, and there was no single case of adult children as donors in this study. Taiwanese parents think that it is natural and medically fit for the parents to sacrifice a kidney to save the lives of loved ones who are still young. Taiwanese parents, particularly the mothers, were the first ones to volunteer instantaneously without consultation with other family members, and they even rejected the donation by the siblings. This hierarchical emphasis was not observed among intersibling donations. Whether this emphasis on vertical relationships (from upper to lower generation) is specific to Taiwanese parental donors or a commonly shared attitude among people in other Asian cultures, needs further investigation.

These features are different from Western cultures, which emphasize a more individualistic, democratic, and free decision-making. Children and adolescents as kidney donors have been reported,[8–10] and discussed in the Western literature,[11] which would certainly not be the case among their Taiwanese counterparts as indicated in this study. The rate of giving-up donation was significantly higher among siblings than in parents, indicating more emotional conflict and psychological pressure among sibling donors. This finding is particularly more pronounced when the prospective donor and recipient are both children or adolescents, as has recently been so well demonstrated in the best-selling novel, *My Sister's Keeper*, in the United States.[12]

The motivation of parental donation of a kidney is perhaps largely based on love or on compensation of guilty feeling toward their children who are critically ill rather than on unconscious altruism or masochism as reported in other cultures.[13] Attitudes of the parents toward donating a kidney after the surgery did not change generally. They never regretted their decision regardless of the outcome of the surgery, although some parents experienced a brief period of grief and loss of confidence in their health after the death of recipients. The attitude of the parents toward kidney transplantation generally depends considerably on the outcome of the surgery. For parents whose recipients had a favorable outcome, the parents continued to show great confidence in kidney transplantation, and expressed willingness to persuade others to receive kidney transplantation. But for those who experienced misfortune, the parents became skeptical about the merits of kidney transplantation. Nevertheless, all parents reported that they have been well served by all family members, and felt that they had performed something "great" for their loved ones regardless of the outcome. Similar experience with more positive feelings of the donors after the operation has been reported elsewhere.[14]

4.2. The value of psychiatric evaluation before surgery

The psychiatric evaluation of donors and recipients before kidney transplantation does not only disclose the underlying family psychopathology, which may later affect the adjustment period of both donors and recipients, but also provides an opportunity to treat the overt psychiatric symptoms. Psychiatrists may not wish to or should not play the "role of the devil" in rejecting their donation based on the evidence of anxiety or depressive symptoms, or obscured informed consent. They should play a more therapeutic role in strengthening the donor's cognitive and coping functions, and in helping the donors obtain more information about kidney transplantation from transplant surgeons, and to be objective and rational as possible in their decision-making for donating a kidney under full cognitive function with the least emotional conflict. The value of the highly systemic interview schedule or self-rating checklist are often limited particularly for parental donors in evaluating psychopathology before the surgery because of the donor's intention to minimize their psychopathology to realize their wish for a kidney donation.

4.3. The need for services for donors

Donation of a kidney by a living donor is a serious medical, social, and psychological crisis which affects the health and quality of life of the donor(s). In the "stage of performance" of the kidney transplantation, all medical attention is usually focused on the effect of the surgery on the recipients. The surgeons and the recipients are the "stars on the stage," and little attention is paid to the donors based on the naive and false assumption that donors can live medically well with one kidney. For this reason, the Committee on Moral and Ethics of the Transplantation Society had declared as early as in 1971 that in kidney transplantation from living donors, consideration of the effects of the surgery on the health and quality

of life of the donors should be given higher priority than that of the recipients.[15]

In view of the prevailing trends in neglecting the care for living donors, there has been an increasing global trend to develop the "donor care unit" to specifically serve for the living donors within the transplantation program.[16] The preliminary findings from our follow-up study on a limited number of relative living donors have supported this need, particularly for those whose recipients had expired.[17]

4.4. The selection of recipients

The recipient needs to receive long-term treatment with immunosuppressive agents and a series of medical follow-up to prevent serious physical complications after kidney transplantation. Specific consideration must be paid to the evaluation of the recipient's personality trait, mental status, or disorders, which may affect the recipient's therapeutic compliance to assure the best benefit from kidney transplantation. The problems would be much more serious in the case of transplantation from a cadaver (than from a living donor) in view of the limited supply of cadavaric kidney for much higher demand.

Those with antisocial personality, moderate to severe mental retardation, a recent history of psychotic disorders, and drug or alcohol abuse/dependence are usually the individuals to be evaluated. But some investigators argue that therapeutic compliance after transplantation may not necessarily relate to past and recent history of mental disorders as mentioned above. Armstrong et al[18] found that only one out of 11 kidney recipients who would fail to comply with the therapies is the patient with the history of above-described mental disorders. Other groups reported that the recipients with a history of mild to moderate degree of mental retardation, mood disorders, and even drug or alcohol use disorders could also have good therapeutic compliance and satisfactory new kidney functions.[19] Although the relationship between therapeutic compliance after kidney transplantation and history of mental disorders of the recipients is still a controversial issue, the evidence of recent history or present major mental disorders, such as psychotic disorders, should be the issues to be carefully evaluated in selecting the recipients to prevent the untoward effects of transplantation. Rating scales, which have primarily been developed to screen the right candidate for liver or heart transplantation, may be applied for kidney transplantation.[20]

While these principles may well apply to kidney transplantation from relative living donors in general, they may, however, not work well when the donor is a parent, particularly the mother who may persuade the surgeon to perform the operation. Most surgeons in the United Kingdom are prepared to perform transplantation from living donors only if the donor is a close relative and persuades the doctor that he or she will feel deprived if this opportunity to help his or her loved ones is denied.[21] Surgeons in Taiwan have adopted a similar attitude in this regard.

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