Decision-Making Process for Living Kidney Donors
Myungsun Yi

**Purpose:** To explore what people experienced when deciding to donate a kidney and to explore associated issues and concerns when they made their decisions.

**Design:** Grounded theory.

**Method:** The data were collected in Korea through semi-structured individual interviews in 1998-1999. A purposeful sample of 14 living kidney donors participated. All interviews were audiotaped and were transcribed verbatim. Constant comparative analysis was done using the NUD*I*ST4.0 software program.

**Findings:** “Wishing to give (a kidney)” was the core category integrating the six subcategories: motives, intervening conditions, inhibiting factors, facilitating factors, donor characteristics, and consequences. Two phases in the decision-making were the deliberation phase and the execution phase. Three decision-making types related to the intensity of “wishing to give” are: high intensity as voluntary type, medium as compromising type, and low as passive type.

**Conclusions:** The decision to donate a kidney was described as a highly complicated process involving not only the medical but also psychological, interpersonal, familial, and financial concerns.

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Kidney transplantation (KT) has high survival rates, with improved quality of life for people with end-stage renal disease, and it costs less than dialysis (Eggers, 1988). Currently the number of KTs performed annually in the world is estimated to be about 415,000 (Park, 1998). Of the two types of KT, living and cadaver, cadaver KT is predominant in the United States and Europe. However, the worldwide shortage of organs from cadaveric donors is forcing greater reliance on living kidney donors (Dunn et al., 1986; Levey, Hou, & Bush, 1986; Spital, 1992, 1993).

In Korea, kidney donations have been predominant since KT was introduced in 1969. Of the 941 kidneys transplanted in 1996, 88% came from living donors (Park, 1998). Although cadaver kidney donations were legalized in 2000, a great need for living kidney donations still exists in Korea.

The decision to donate a kidney, however, generates significant stress for potential donors because the procedure is life-threatening and irreversible. Potential donors in previous studies tended to be ambivalent about making their decisions in the context of medical information and family pressure (Simmons, Hickey, Kjellstrand, & Simmons, 1971). Family pressure and conflict (Hilton & Starzomski, 1994; Simmons et al, 1971; Smith et al., 1986) might result in the decision to not donate a kidney (Bratton & Griffin, 1994). Also the decision often must be made under time constraints, thus increasing the level of stress for potential donors (Simmons, Marine, & Simmons, 1987). On the other hand, Land (1989) and Levey and colleagues (1986) reported that the decision to donate a kidney is voluntary, without hesitation or much consideration.

Motives in donating a living kidney have also been described in the literature. Reported motives have varied, including parental love or helping family members (Hilton & Starzomski, 1994; Kim, Yoo, & Kim, 1995; Rhodes, 1986; Simmons et al., 1971), religious beliefs (Farley, 1982; Schumann, 1974), meeting the expectation of family members (Smith et al., 1986), responsibility and duty (Diethelm, 1989; Rhodes, 1986), or guilt (Schumann, 1974). Others (Levey et al., 1986) indicated the motives derived from their own psychological needs rather than solely out of concern for the recipient, so as to improve self-esteem or status or to prevent illness.

Thus reports of kidney donation are sometimes consistent, and sometimes contradictory. And only limited information is available from the perspectives of the donors. With

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integrated knowledge on decision making for donating a living kidney, health professionals could help potential donors decide in a more ethical way and could reduce problems that might occur during the decision process.

The purpose of this study was to explore what donors experience when they decide to give a kidney. The research question was: What is the process of decision making of the donors and what are the major issues and concerns when donors carry out the decision to donate a kidney just before the nephrectomy?

**Methods**

**Setting and Sample**

This exploratory study was based on grounded theory methodology (Glaser & Strauss, 1967; Strauss & Corbin, 1990). The data were collected in Korea during 1998-1999 when the organ procurement and sharing process was managed by hospitals before the Korean Network for Organ Sharing was established in 2000 to manage it nationally.

To collect the data, the organ transplantation coordinator of the hospital recruited potential participants who were most likely to describe their experiences regarding difficulties or issues in decision making. The participants' human rights were protected by following the research protocols approved by the human subject review committees at the school and at the practice setting. As the analysis progressed, sampling was based on the theoretically relevant concepts identified in the analysis. A purposive sample of 14 kidney donors or prospective donors provided the data for the study.

Four male and 10 female kidney donors participated in the study. They were all Korean and their mean age was 39. Five were Buddhist, four Protestant, two Roman Catholic, and three stated no religious preference. Their relationships with the recipients were three mothers, six brothers or sisters or in-laws, three spouses, and two had no familial relationships.

**Data Collection and Analysis**

Data collection and analysis proceeded in a circular form, using grounded theory. The data were collected via in-depth individual interviews lasting 1 to 3 hours. Individual interviews seemed to help the participants talk more freely than in interviews with family members present, thus obtaining more credible data (Hilton & Starzomski, 1994). To obtain data that best represented the experience and situation, most interviews were done within a week before or after the nephrectomy. Four participants were interviewed on the day before surgery. All interviews were audiorecorded and were transcribed verbatim. The NUD*IST 4.0 software program was used for efficiency, saving time (Conrad & Reinharz, 1984), and increased trustworthiness (Conrad & Reinharz, 1984; Richards & Richards, 1994).

Data were analyzed using constant comparative analysis that involved moving back and forth among the data sets. After the initial data were collected from 10 participants, they were analyzed by examining words, phrases, and sentences to generate codes. Further analysis helped to develop categories, their properties and dimensions by comparing codes. Connections were made between the categories using a paradigm model that included conditions, context, strategies, and consequences. Finally, a theoretical model was constructed by comparing categories to discover the core category that integrated all other categories and accounted for much of its variations. Subsequently, interviews with four more participants and three follow-up interviews were performed to verify, saturate, or refine these categories and their relationships.

**Findings**

From the constant comparative analysis of the data, “wishing to give (a kidney)” was identified as the core category integrating other categories and accounting for much of the variation. The importance of “wishing to give” was well described by one participant who donated a kidney to his elder brother.

The most important thing in the decision-making process is really wanting to give a kidney. If you really want to give, then you will see everything positively. Nothing else bothers you at all.

One major property of “wishing to give” was intensity. In terms of the intensity of “wishing to give,” three different types of decision-making were identified: high intensity as voluntary type, medium as compromising type, and low as passive type.

Six subcategories were also found: motives, intervening conditions, inhibiting factors, facilitating factors, donor characteristics, and consequences. To portray the whole experience of donating a living kidney, a framework incorporating the core category and subcategories was formulated (see Figure 1).

As shown in Figure 1, two distinct phases emerged. The first phase was the deliberation phase to give a kidney and contained “wishing to give,” “motives,” and “intervening conditions.” The second was the execution phase that occurred during the tissue compatibility tests, involving “inhibiting factors,” “facilitating factors,” and “donor characteristics.” Finally, “consequences” included psychosocial status after the final decision to donate a kidney but before the operation.

**Deliberation Phase: “Wishing to give”**

The deliberation phase indicates how donors began having thoughts about giving a kidney to the potential recipient before the decision to begin testing. This phase takes either a short time or a very long time, such as 5-10 years, depending on the characteristics of the chronic process of renal failure of the potential recipient.

The essential reason to give a kidney was to save a life or to improve the health of the recipient, while believing that the donor could live a life without major complications with only one kidney. However, many motives were involved with “wishing to give” a kidney. The major motive that was
Figure 1: Decision-making process for donating a kidney.

identified among the participants was embedded within the family. The donors wanted to keep the family intact and harmonious with love. Repaying a previous favor to the family recipient was another major motive influencing "wishing to give." In the case of brother or sister donations, some donors were family troublemakers who previously had made the family lose face because of his or her misbehavior. Others were debtors to the potential recipient or the family itself, and donation was regarded as repaying a debt.

The reason I am going to give my kidney to my sister is because I was the most trouble-making one among six siblings. I was such a bad student at school, fighting with friends and hanging around outside.

Sympathy, duty, freedom from burden of caring, and fear of guilt were other factors. Phrases such as “I met him and now he is my husband, so I need to do my best,” or “I feel like God will condemn me if I don’t give him my kidney” reflect these motives or reasons for donating a kidney.

Religious beliefs also were major motives, especially in the case of unrelated donors. The donors were eager to practice religious beliefs such as alms in Buddhism or “love thy neighbor” in Christianity. In this case, the intensity of “wishing to give” was the highest among other kinds of donor-recipient relationships.

In addition, emotional intimacy between the donor and the recipient influences the desire to give. It was related closely to the intensity of “wishing to give.” The more intimate they were, the higher the intensity of “wishing to give” was. Economic benefits resulting from KT also influenced the desire to give. This situation applied when potential recipients were not well-adjusted to dialysis, causing large expenses because of various physical complications, such as anemia or anorexia. The difficulty of purchasing a kidney on the black market is another factor that influenced participants to make up their minds to proceed with compatibility tests. All participants except unrelated donors had at one time or another seriously considered purchasing a kidney, although it was illegal and unethical. But they had to give up after they realized that an unrelated kidney had a high rejection rate, finding the right kidney was time-consuming, and purchasing a kidney would be too costly.

Execution Phase: Three Types

The execution phase indicates how potential donors follow through with the decisions to have the operation to give a kidney. This phase includes tissue compatibility tests that usually lasted 3 to 6 months. Three levels of intensity of “wishing to give” emerged: high intensity as voluntary type, medium as compromising type, and low as passive type (see Table 1).
Table 1. Decision-Making Types of Participants

<table>
<thead>
<tr>
<th>Intensity of wishing to give</th>
<th>Type</th>
<th>Donor (age)</th>
<th>Recipient (age)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>Voluntary</td>
<td>Mother (59)</td>
<td>Son (25)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mother (47)</td>
<td>Son (24)</td>
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<tr>
<td></td>
<td></td>
<td>Brother (38)</td>
<td>Brother (48)</td>
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<tr>
<td></td>
<td></td>
<td>Sister (41)</td>
<td>Brother (34)</td>
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<tr>
<td></td>
<td></td>
<td>Wife (32)</td>
<td>Husband (35)</td>
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<tr>
<td></td>
<td></td>
<td>Niece (38)</td>
<td>Aunt (55)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other (37, Female)</td>
<td>Other (56, Male)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other (38, Male)</td>
<td>Other (40, Male)</td>
</tr>
<tr>
<td>Medium</td>
<td>Compromising</td>
<td>Sister (33)</td>
<td>Sister (29)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Brother (32)</td>
<td>Sister (41)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wife (38)</td>
<td>Husband (45)</td>
</tr>
<tr>
<td>Low</td>
<td>Passive</td>
<td>Mother (30)</td>
<td>Son (7)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wife (38)</td>
<td>Husband (39)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Brother (26)</td>
<td>Brother-in-law (52)</td>
</tr>
</tbody>
</table>

Voluntary type. When “wishing to give” a kidney was intense, the course of decision making during the execution phase was smooth, active, and straightforward. Among the 14 participants 8 were of this type. The intimacy between the potential donor and the recipient was strong in cases of blood relation. And all unrelated donations also were of this type.

Participants of this type actively tried to become donors, discouraging other relatives as potential donors by taking the compatibility tests alone. They were determined to give a kidney. However, in the end donation was a result of thoughtful consideration over a long period rather than that of a quick decision as described in previous reports (Fellner & Marshall, 1968, 1970; Levey et al., 1986).

If someone asked me what the most important factor was in my decision to donate, I wouldn’t have one to answer. The decision came naturally, very naturally, and not out of impulse, almost as if I had been preparing for it for a long time. It also came about slowly, not in response to some outside factors, but rather ripening slowly as time passed by.

Because people of voluntary type had a high intensity of “wishing to give,” only a few factors pertained to the decision. The suspicion of the true motives of others, such as family members, health care workers, or even the potential recipient, was the one difficulty they had in the decision making. Therefore, some donors entered the process of compatibility tests without telling their family members. In some cases the refusal by the potential recipients hampered decision making, requiring persuasion of the recipients and their family members.

Another difficulty in donating a kidney for people of voluntary type came from the tests themselves. Before taking the compatibility tests, these participants thought of only the operation for kidney removal. But the testing procedures were very time-consuming and painful, and submitting to these procedures was difficult for some participants.

Participants of the voluntary type did not need any facilitating factors or information during the execution phase.

Instead they were worried about whether the test results indicated a mismatch—unlike other participants who wanted to be mismatched. Participants of this type tended to be independent and assertive. Thus they could firmly decide for themselves without relying on others, and no family members tried to interfere with their decision.

Finally when all compatibility tests were positive, all participants in the voluntary type felt relieved and comfortable. Some even felt thankful for being able to give. They were also thankful to their immediate family members, especially spouses, for their understanding. They also had a newfound calm in which to give thoughtful consideration to donating a kidney in excellent condition, by keeping themselves healthy. For example, most participants tried not to catch a cold, and tried to stop smoking and drinking. Some even had their abdomen massaged to give a good healthy kidney to the recipient.

Compromising type. When the intensity of “wishing to give” was moderate the decision-making process was complicated, involving more inhibiting as well as facilitating factors in careful consideration. The process with this type started with passive participation in the compatibility tests, and then became voluntary as the tests turned out to be positive. Three of the 14 participants were of this type.

At first, the potential donors of this type started taking compatibility tests with other candidates, suspecting that their tissue would be matched with the potential recipients. However, when the tests were positive, they became active, feeling that they had no other choice. They began to give up hope not to be selected as a donor. One sister explained the reason she was chosen as a donor among several brothers and sisters.

The hospital asked all of us [the family], and tested all my brothers and sisters. After the results arrived we had a family meeting, and somehow the decision was quickly made. My eldest sister did not have a healthy kidney. They said she had a benign tumor there. Suddenly it was between my elder sister and me. And before you know it, I was selected [resigned expression].

The decision making of this type was more deliberate involving many more factors than that of the voluntary type. Participants of this type feared the operation and pain and were worried about living with only one kidney, but those of voluntary type did not. They also experienced severe difficulties with family members, especially with their spouses and children.

Yet when the test results were positive, these participants began thinking positively and accepted the thought of donation. They considered their personal status, such as their age, health, and job characteristics, compared to other candidates, to identify good reasons or justifications to accept. The younger and healthier ones were inclined to think the would adjust better after the operation than did the others. The white-collar workers tended to think they would adjust better after the operation than did the blue-collar worker because of the comparatively low intensity of physical work.

After all these factors were considered the participants began to persuade the family members who were opposed to...
donations. At this phase assertiveness helped them not only to defend themselves but also to persuade the family members who were opposed. Trustful relationships with spouses facilitated successful persuasion as well.

Unlike those of the voluntary type who strongly refused any monetary payment or any type of gifts because it would imply payment for their kidneys, most participants of the compromising type had received economic compensation. They could not resist beneficence from the recipient and took it for granted. At the same time the recipients and their family members thought that giving payment to the donors was their duty; because the donors shared their health with the recipients, recipients and family members wanted to share wealth with donors (Yi, 1999).

When the time came to decide, all participants of the compromising type had no reservations. Like the participants of voluntary type, they all felt relieved and comfortable, keeping themselves healthy to give a healthy kidney.

Passive type. When the intensity of “wishing to give” was low, the process of decision making was volatile, although the potential donors did not give up on donating a kidney. This process was characterized by reluctantly taking compatibility tests and remaining passive throughout the decision-making process. It proceeded with more agony, deliberation, and ambivalence than that of the compromising type. Three of 14 participants were of this type.

The participants decided to take the tests either reluctantly or by active persuasion of the family members, fearing that the test results would match with the potential recipient. They also reported fear of the operation and pain.

The participants tended to have low levels of intimacy with the recipients, as in the case of donating to in-laws or spouses who no longer loved each other. Their major motives were duty, responsibility, or freedom from caring all the time for the recipient, rather than love or sympathy keeping the family intact and harmonious. One woman who gave her kidney to her husband said:

> People ask me for motives, about why I did it. I always reply, 'I did it for my kids'! ... I really did give it for my kids. Now, we really don't love each other, rather we just live together for the kids.

All participants of this type were persuaded by family members with economic compensation. At the same time, they were more active and explicit in seeking economic compensation unlike those of the compromising type, in which it was more implicit. No sympathizers came forth to side with them and no family members opposed the donors' decision to give a kidney, unlike in the case of the compromising type. Therefore, they had to rely more on the health care workers, seeking more precise information on the operation and prognosis. The passiveness in giving a kidney remained even after the final decision to donate a kidney was made. They mulled on it over and over trying to resolve many complicated thoughts and kept seeking reassurance that it was a pure and voluntary decision, right up until the surgery.

Others say they felt comfortable when they finally decided to donate a kidney, but when I finally decided, I still felt turmoil for 3 days... I looked at myself in the mirror, asking myself, "Do you really think you did the right thing? Is it really coming from your heart?" I looked into my eyes to try and read my mind. It was hard for me for 2 to 3 days. But I made up my mind, and then I was relieved. I didn't have any afterthoughts. I was finally free of my indecision.

Finally the participants of passive type became comfortable and relieved like the other types, no more bearing the heavy burden. But they still had fear of the operation and pain, and were worried about the prognosis and life after the operation.

Conclusions

This study resulted in an integrated framework to describe and explain the whole process of donating a living kidney, identifying types and issues as well as factors closely related to the decision. The findings showed that the decision to donate a living kidney involved numerous psychosocial, interpersonal, and financial factors, while medical considerations were relatively limited. Consistent with the report by Land (1989) the decision for a living donation was more social than medical.

These findings confirmed the need to assess various areas related to kidney donation. Family dynamics and the relationships between the donor and the recipient should be assessed carefully. Health professionals, donors, and even recipients should be aware of the stressful situation that potential donors face. The transplant team needs to support potential donors to resolve conflicts and to relieve the burden or stress so as to be better prepared before the surgery, especially for people who have a medium to low degree of wishing to give a kidney to the recipient. Education and counseling for potential donors should be focused on their understanding to undergo compatibility tests as well as the surgical procedure and the acceptance of these risks. Ultimately the health care team should support potential donors to make sure their final decision is objective and safe. These actions might help prevent problems (Bennett & Harrison, 1974) or suicide (Weizer, Weizman, Shapira, Yussim, & Munitz, 1989) that could occur after the donation.

This study was based primarily on the point of view of the donors. Further research should be focused on viewpoints of others, such as recipients, siblings, spouses, and the family system as a whole to ground the conceptualization in a broader context. Cross-cultural studies can advance understanding of the effects of culture and society on the experience of decision making for donating a living kidney.

References


Living Kidney Donors