The donation process of living kidney donors

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Abstract

Background. The rates of both genetic and non-genetic living donors are increasing. However, previous research has almost exclusively explored the decision-making of genetic donors. Therefore, in this study both genetic and non-genetic donors are investigated with focus on their whole donation process.

Methods. Thirty-nine donors were interviewed the day before nephrectomy and 3 weeks afterwards. Twenty-three donors were genetic relatives, 16 were not. The interviews were analysed qualitatively, mainly by narrative structuring.

Results. All donors but one passed seven steps in the donation process. They included: (i) awareness of suffering; compassion and empathy; (ii) imminence of transplantation; recognition of oneself as potential donor; (iii) information acquisition and deliberation; (iv) attribution of responsibility to oneself; announcement of decision to donate; (v) examination; maintaining the decision; (vi) facing nephrectomy; and (vii) postoperative experiences. Two types of decision-making were displayed: immediate and later announcement of decision. Half the donors belonged to each type. Various relationship groups displayed different types. The examination period was the most stressful time, partly due to imperfect coordination and excessive time-wasting. One-third found postoperative pain the most painful experience ever. There was a lack of attention to regressive needs and to recognition of the deed.

Conclusions. The two types of decision-making seem similar in ethical requirements. It is not a genetic or non-genetic relationship per se that determines what kind of decision the donors make. Psychological support, especially during Steps 5 and 7, should be improved and the donors included in a structured donation programme. Possible health care ambivalence toward living donation should not affect the donors.

Keywords: decision making; interviews; living kidney donors; motives; organ donation; transplantation

Introduction

Kidney transplantation is the preferred renal replacement therapy, bringing the best quality of life for the recipients. Kidney donation from a living individual has a long tradition and many transplant centres accept donation from both genetically and non-genetically related donors. In Sweden, the rate of living donors was 47% in 2000 (Swedish National Board of Health and Welfare, 2003). A prerequisite for donation is that the donor is healthy and has made a voluntary, informed decision. The mortality rate of donor nephrectomy is about 0.03% and the rate of serious complications seems to be about 0.2% [1]. Long-term risks are considered low and survival rates are higher for kidney donors than the general population, evidently because of the selection criteria [2,3].

All major surgical procedures are risky. Though mortality and morbidity are low, it is an extraordinary act to have a healthy part of one’s body removed and given to another person. It requires self-sacrifice, courage and determination. It is important to explore the donation process, including the decision-making, from a psychological perspective. The donation process is defined here as the process that evolves within the donor from the first perception that the recipient will need a transplant in the future to the experiences of the nephrectomy. Therefore, the aim of this study, which is part of a larger project on living donation, was to explore the donation process of a heterogenous group of genetically and non-genetically related living kidney donors. Previous research on this issue has mostly included only genetically related donors. The extension
of the donor pool to spouses, in-laws and friends possibly means that the process displays different elements compared to genetic relatives.

Previous research

Eisendrath et al. [4], and Fellner and Marshall [5] were the pioneers in studying the decision-making of living donors, followed by Simmons et al. [6] in their comprehensive work on donors and recipients. These researchers found that most donors seemed to make their decision to donate without any deliberation, as soon as they became aware of the need for a transplant. Fellner and Marshall [7] suggested that the rational model of decision-making was not applicable in this context. This model stresses the collection of information and production of action alternatives, the conscious deliberation and evaluation of these alternatives, and the choice of one of them [8]. Instead the model of moral decision-making proposed by Schwartz [9] would fit this kind of decision better. This model includes three phases: becoming aware that a specific action has consequences for another’s welfare; ascribing responsibility to oneself for this action; and accepting the moral norm at issue, e.g. the virtue of helping someone in distress. According to this model the decision can be made promptly because no deliberation is included. Hilton and Starzomski [10] studied the decision process from a family perspective. They also found that ‘straightforward’ decision-making was most frequent among the 10 donor families in their study. More recently, Schweitzer et al. [11] reported on an ambitious donation counselling programme where problematic cases were offered a moratorium instead of being dismissed. It is not clear from the article but it seems that these 67 presumptive donors were either blood relatives or spouses, who mostly made a ‘straightforward’ decision. In another recent study on 12 presumptive donors where three people had a non-genetic relationship to the recipient, all but one (a friend) made their decisions instantaneously [12].

Thus, according to previous research, most genetically related donors made immediate decisions and few deliberated about the decision.

Subjects and methods

Thirty-nine living kidney donors were interviewed the day before their surgery and three times during the following year. However, this study only makes use of the first and second interviews; the latter were done 3 weeks after the operation. The informants were recruited from two transplant centres in Sweden in consecutive order during 2000. Because men were under-represented, the inclusion period for men was prolonged into the first months of 2001. Nobody declined participation. Most interviews were performed at the transplant centres and a few in the donors’ homes. Twenty-three donors were genetic relatives, 16 were not. Both donors and recipients were adults. Only Swedish-speaking individuals were included to obviate language problems; this excluded one non-Swedish-speaking donor. Educational levels varied from elementary school to university graduates, and occupational backgrounds were diverse. Sex, age and relationship of the donors are given in Table 1.

An open-interview method was chosen to allow the informants to raise unexpected issues. However, an interview guide guaranteed that pre-determined issues were covered to permit comparisons between the informants (see Appendix). The author, a psychologist who had no affiliation with the departments involved, did all interviews. This was advantageous in making the informants feel free to express even critical opinions, i.e., to get rich, valid material.

The interviews were audiotaped, transcribed and analysed mainly by narrative structuring of the material [13,14]. The analyses focused on the understanding and meaning that the informants gave to their experiences of the donations. In this task, seven different steps constituting the donation process (the story) were identified (Table 2). They were based on a semi-chronological sequence of the events that the donors considered significant in the process. The donors’ experiences were then summarized for each step. Also, two different types of decision-making were identified (Table 3), and the donors were classified accordingly (Table 4). This classification was also done by a co-judge, another psychologist. Both judges agreed upon all classifications. This indicates that the boundaries between the categories were distinct and that there were no difficulties in classifying the informants by decision type. Finally, the

### Table 1. The donors’ sex, age and relation to the recipients. (23 women, 16 men)

<table>
<thead>
<tr>
<th>Relationship to the recipient</th>
<th>Age (years)</th>
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<tr>
<td></td>
<td>33–39</td>
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<tr>
<td>Mother (n = 8)</td>
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<td>Father (n = 5)</td>
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<tr>
<td>Sister (n = 4)</td>
<td>1</td>
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<td>Brother (n = 4)</td>
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<td>Daughter (n = 2)</td>
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<td>Wife (n = 4)</td>
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<tr>
<td>Husband (n = 3)</td>
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<tr>
<td>Female in-law relative (n = 3)</td>
<td>–</td>
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<tr>
<td>Male in-law relative (n = 1)</td>
<td>–</td>
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<tr>
<td>Female friend (n = 2)</td>
<td>1</td>
</tr>
<tr>
<td>Male friend (n = 3)</td>
<td>3</td>
</tr>
<tr>
<td>Total (n = 39)</td>
<td>10</td>
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Mean age 48.85 ± 1.42; mean age females 48.83 ± 1.73; mean age males 48.88 ± 2.49.

### Table 2. Seven steps in donation process

1. Awareness of suffering. Compassion and empathy
2. Imminence of transplantation. Recognition of oneself as a potential donor
3. Information acquisition and deliberation
4. Attribution of responsibility to oneself. Announcement of decision to donate
5. Examinations. Maintaining the decision
6. Facing nephrectomy
7. Postoperative experiences
findings were interpreted in terms of ambivalence, conflicts and defence strategies.

Results

Steps in the donation process

The donation will be described as a seven-step process (Table 2). The time order of the first four steps varied between the donors but all except one passed through all of the seven steps. Quotes from informants appear within quotation marks in the following.

1. Awareness of suffering, Compassion and empathy. All recipients except three had been ill for many years, and most donors were well acquainted with their diseases and afflictions. They found the recipients' situations ‘heart-breaking’. Two donors were afraid that the recipients would commit suicide because they found the dialysis unbearable, and two others believed that the recipients would soon die if they did not get a transplant.

2. Imminence of transplantation. Recognition of oneself as potential donor. The insight that transplantation was imminent and that one was a potential donor came for four informants with the recipient’s question on donation, for two informants with the recipient’s doctor asking, and for three others with information from the doctor that they were in the category of potential donors. The others understood themselves that they were possible donors or inquired about this. In nine cases, a family member had already been tested and found incompatible. This was the case for most in-laws and friends and they had not been aware that they could volunteer as donors before the family members were eliminated.

3. Information acquisition and deliberation. Many donors gathered information on their own early in the process, and all donors also got information from the nephrology and transplantation departments about health statistics, procedures, risks and economic conditions. However, information was gathered continuously until nephrectomy, not only during Step 3. Nine informants who donated to someone other than their children checked their children's health or blood groups in case the children might need a transplant in the future. Thus, they wanted to prioritize their offspring and as far as possible ensure that the children would not need help. The option of a necro-kidney was not considered a serious alternative due to the long waiting list. The crucial issues concerned whether one was healthy enough to handle the operation and could live one's life as previously. However, seven parents expressed a willingness for self-sacrifice, meaning that they themselves were prepared to take on dialysis instead of their children or even to die.

4. Attribution of responsibility to oneself. Announcement of decision to donate. For 20 donors the information that it was time for transplantation immediately triggered the announcement of the decision to donate. Thus, Steps 2 and 4 occurred without perceived time delay. Already during Step 1 they had more or less subconsciously recognized their candidature as donors in an indefinite future and adapted themselves to the prospect of the operation. They were mentally well prepared and found it ‘self-evident’ to donate. They did not perceive any decision-making. When it was time the decision was already made.

Only two of these informants seemed to have made the announcement impulsively, without previously knowing the need for a transplant. One informant donated to a friend. He had a professional interest in ethics and had adopted a consciously altruistic attitude toward other people. Thus, he was mentally prepared to act, but the ‘target’ for his helping had previously been unidentified. The other informant was a daughter, who donated to her divorced father, to whom she was very devoted. She did not even know that living donation was possible until her father told her that his siblings had refused to give. She was not prepared for donation and yet made an immediate decision.

Nineteen donors identified themselves as potential donors after the need for a transplant had become imminent and made their announcement to donate between 2 days and more than a year after they had received information about this need. For 13 donors it took less than 2 months, for three donors 2–6 months, and for three donors 7–13 months. They had consciously weighed the costs contra the benefits. Of these

<table>
<thead>
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<th>Table 3. Characteristics of the two types of decision-making</th>
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<tr>
<td>Immediate announcement of decision</td>
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<tr>
<td>Decision announced immediately when donor was informed of the imminent need for a transplant. Step 3 came before Step 2 meaning that conscious and unconscious deliberations occurred early in the process. Steps 2 and 4 coincided, i.e. recognition of oneself as possible donor immediately triggered attribution of responsibility to oneself</td>
</tr>
<tr>
<td>Later announcement of decision</td>
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<tr>
<td>Decision announced after conscious deliberation of pros and cons. Deliberations were usually short but in one case over a year. All steps were taken in order from 1 to 7</td>
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<th>Table 4. Types of decision-making related to kinship</th>
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<tr>
<td>Type of decision-making</td>
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<td>--------------------------</td>
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<tr>
<td>Immediate announcement (n = 20)</td>
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<td>Later announcement (n = 19)</td>
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19 donors, 16 thought it was an easy decision to make. This group had also usually been aware of the recipient’s need for a transplant for a long time and had prepared mentally during this time. What remained was identification of oneself as a possible donor, a conscious summary of arguments and attribution of responsibility for the donation to oneself. Three donors regarded the decision as difficult and two of these felt intermittently strong anxiety during the examination period. They thought that morally they had no choice but to donate, though the transplant teams and the nephrologists assured them that they could opt out even on the operation day.

All donors reported that they made their decisions on their own. They perceived no external pressure to donate.

5. Examinations. Maintaining the decision. Before the potential donors were accepted for nephrectomy, they had to undergo a series of medical examinations, most of which were administered by the nephrological clinic in the county where the recipient lived. It is this county council that reimburses all the donor’s expenses in connection with the donation that are not compensated by the health insurances. This period was at least 6 months for most donors, which most of them thought had been far too long. The length of time depended on the waiting time for different tests and factors in relation to the recipients such as general health and the remaining function of the kidneys. However, in several cases the delay depended on a lack of coordination of the examinations and on awkwardness in dealing with the donation. One-third of the donors were critical of the management, and the delay was a stress factor for many informants. The anxious wait for the test results also added to the stress. Furthermore, the waiting time between the final acceptance of the donor and the operation time was usually perceived as too long. Because they usually had no contact with either the nephrological or transplant clinics during this time they felt lost and wished that they had had follow-up contacts, at least by telephone.

Most donors, especially those who felt an obligation to donate, thought that the possibility to withdraw—stressed by the doctors—was just a myth. The repeated information that they could withdraw was sometimes annoying and regarded as a doubt about the decision. Several donors said that it was necessary to be mentally strong to carry through the donation: to be determined and not start hesitating. Thus, the decision had to be defended and maintained.

Over half the donors regarded the examination period as the worst step. The need for support was greatest during this step, as existential questions were also activated, e.g. about life and death and the meaning of life. Many informants found it difficult to specify these issues, and such aspects of the donation were mostly unnoticed by the staff. Members of the immediate family was not regarded as suitable discussion partners because they were often anxious about the operation and might have interpreted a conversation about existential questions as a hesitation.

In general the donors felt support and even admiration from their social network. They expressed a deep trust in the transplant team. After having passed the examinations, they were proud of their healthy bodies and the fact that they were capable of ‘delivering good material to the recipient’.

6. Facing nephrectomy. Donation. Three donors made some preparations in case they were to die, such as writing a will. The day before the surgery, the donors were extremely committed to proceeding and somewhat elated.

Sometimes the donors were informed that the operation might be postponed for a week or more due to operation room logistics. After having mobilized much energy and resolution at the operation, the postponement seemed to release negative feelings and anxiety that hitherto had been suppressed. They felt that the decision was spoilt and had to be reconsidered. This indicates how strong the commitment had to be to reduce the cognitive dissonance that characterized their situation [15]. This means that there were inconsistent elements on which this decision (as well as many other decisions) was based; the positive elements for the decision have to be bolstered and the negative ones ignored or reinterpreted.

7. The postoperative experiences. All nephrectomies were successfully accomplished and the kidneys transplanted. Twenty-one nephrectomies were performed with open surgery and 18 laparoscopically. (Two of the open surgeries were flank incisions, 19 were anterior retroperitoneal approaches.) Three weeks after the surgery, 54% of the donors stated that the operation had been easier than expected; 44% reported that this was the most painful experience they had ever had. The pain sensations were related to gender, age and surgery technique (Table 5). The differences between some of the subgroups are suggestive but not statistically significant tested by χ² analysis. (Here a quantitative element is added to this qualitative study, as I look upon these two research approaches as complimentary.) Of the 20 women who had given birth to a child, 15 thought that the nephrectomy was more painful than the delivery, because the pain remained longer. Six donors who found the donation easier than expected still classified it as their ‘worst’ experience due to their restricted experiences of pain. Yet almost all informants thought that the analgesia was well handled by the staff even though they were not free of pain; only one informant was critical about not receiving help when he needed it.

The postoperative care was unanimously characterized as ‘super’. However, seven donors wished for better psychological care in some critical situations such as regressive reactions, pain attacks and transplant rejection episodes. Eleven donors (eight women and three men) experienced feelings of being abandoned, exploited and ignored by the staff. ‘They almost threw me out because they needed my bed for someone
The donors announced their decision to donate at the latest during the first medical examinations. However, several donors perceived that they had to continuously remake their decisions as the doctors routinely checked the intentions of the future donors at appointments and stressed that they could refrain any time until they lay on the operation table.

As suggested in the previous section, there were two types of decision-making (Table 3). Table 4 gives some indications about the distribution of decisions. In all relationship groups except the offspring there were individuals with both immediate and later announcement. However, the parents and offspring usually made an immediate announcement, whereas in-laws, friends and siblings usually announced their decisions later. The spouses were evenly distributed over the two types.

The two sisters who made immediate announcements had special relationships to the recipients. They were older sisters in split families and had partly adopted maternal roles towards their younger sibling. The only person among the in-laws who gave an immediate announcement was a step-father with no children of his own. By donating he thought he would get ‘a real blood-relationship’ to his step-child to whom he was very attached.

The female donors tended to make an immediate announcement more often than the males (61 and 38%, respectively). This difference may be explained by women’s better perception of people in distress and their early identification as helpers as part of their gender role.

Discussion

Methodology

The sample of informants can be regarded as representative of Swedish male and female donors during this period in focus and comprised 43% of the Swedish donors during the inclusion period. However, the sample is still small and not suited for statistical analyses (nor was this the intention). This study demonstrates how individuals who carried through on their kidney donations perceived the donation process. Some of these experiences occur as a function of the health care system, which make these issues generalisable to other systems with similar frames and culture. On another level there are ideas and thoughts that are affected by the existential situation of the informants and therefore should be found in all constellations of presumptive donors. However, we cannot conclude that the ideas and experiences of these informants are all-inclusive due to the small sample.

One weakness is that only individuals that actually became donors were included. This means that we miss information on what makes (medically suited) people refrain from donation. We cannot simply postulate that problems experienced by donors become too severe for non-donors. It seems important to conduct a study including all individuals that have any contact with health care in this question in order to better understand also non-donating presumptive donors’ reactions and doubts.

The decision-making

The steps in the donation process were the same for all donors except one, but there were differences in the time order of the first four steps, which comprised the decision-making, and in the awareness of the considerations. Some steps are similar to phases of the moral decision-making model [9] and others to the rational decision-making models [8]. However, there does not seem to be any intrinsic opposition between these models. Even in moral decision-making there may be deliberations about responsibility for an action and which moral norms are applicable in a certain context or relationship; in the rational model, moral norms may be an important factor in the weighing of pros and cons [6]. Also, Janis and Mann [8] regard Schwartz’ model as a ‘satisfying’ rational model.

The terms ‘later’ and ‘immediate’ announcement of the decision have been selected to stress that it is not the moment when the decision was made, but when the recipient was offered the kidney that is concerned. This is a more exact statement because at least half the donors were actually unaware of when their decisions were made. In previous research the focus was on the

Table 5. Perioperative pain sensations of total group and subgroups

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<tr>
<th>Operation experienced:</th>
<th>Worst pain ever sensed (%)</th>
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<tr>
<td></td>
<td>as easier</td>
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<tr>
<td>Total group (n = 39)</td>
<td>54</td>
</tr>
<tr>
<td>Open surgery (n = 21)</td>
<td>48</td>
</tr>
<tr>
<td>Laparoscopic (n = 18)</td>
<td>61</td>
</tr>
<tr>
<td>Men (n = 16)</td>
<td>50</td>
</tr>
<tr>
<td>Women (n = 23)</td>
<td>57</td>
</tr>
<tr>
<td>&gt;55 years (n = 12)</td>
<td>75</td>
</tr>
<tr>
<td>&lt;55 years (n = 27)</td>
<td>44</td>
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donors’ conscious perception of when their decision was made [6,7,10]. However, if we regard the informants’ descriptions of their decision-making in the context of the whole process, we can see that what seemed to be an ‘immediate’ decision had been in progress for a long time or had even been made long before the announcement, more or less subconsciously. Some donors tended to stress the immediacy as a way of showing that they felt no hesitation about the decision. They were eager to be donors and keen to show their determination. Such behaviour might contribute to depicting the decisions as more impulsive and less deliberated than they really were. This might in turn contribute to the doctors’ needs to ensure that the presumptive donors still keep to their previous decisions.

Decision-making and relationship to the recipient

In this study the distribution of the decision-making patterns was even, whereas in previous studies a minority of the donors made conscious deliberations before their decision. Most previous studies explored only genetic relatives, whereas in this study 40% of the informants were not. Sixty-five percent of genetic relatives and 31% of the others gave immediate announcements. This reflects the prevalent pattern of family responsibility in Swedish society, which leads to early recognition of one’s role as a presumptive donor to one’s child or parent. The two sisters and the step-father who had semi-parental relationships to their recipient can be included here. There are also strong norms of responsibility concerning spouses. The deliberations of the spouses were connected to responsibilities for their children and sometimes to personal anxieties. The siblings deviated from the other genetic relatives; all but those who had a parent-like relationship to their recipient gave later announcements. This suggests that siblings in Sweden are not expected to take responsibility for each other to the same degree as parents and offspring.

There seem to be no differences in types of decision-making between genetic and non-genetic donors. Rather, the differences seem to vary with the quality of the relationship than with the genetic relation (compare spouses and siblings).

A crucial question is whether either of the two types of decision-making is better. ‘Better’ means here that the decision-makers are aware of what they are doing and that the decision is autonomous, i.e. they adhere to requirements of informed consent, which is a cornerstone in medical ethics [16]. There were no differences in these respects between immediate and later announcements, and the evaluation of the risks was similar in both types of decision-making. All donors regarded their decision to donate as well grounded.

Need for additional support

The donors perceived their first announcement to donate as a final promise, but because the medical staff repeatedly made inquiries about this decision, even Steps 5 and 6 in the donation process were vaguely perceived as a prolonged decision-making. The medical examinations that might prevent the donation, the missing time schedule and the floating time perspective often contributed to a sense of insecurity and being in ‘no man’s land’. Thus, the need for support was strongest during the examination period but was not always met by the health care. Rather, the donors seemed to have met an ambivalent attitude. Also, even if the donors were determined to donate, they needed to talk about their situations and what would happen in the future as well as about existential issues. However, they were afraid that such conversation would be defined as hesitation and that they would be dismissed. Thus, they often had no outlet for these thoughts, as they usually had not wanted to bother their families either.

Furthermore, during the immediate postoperative period, the donors needed extra attention. Many informants found the pain worse than expected [17,18]. Those operated with an open procedure tended more often to classify the pain as their worst experience compared to those operated laparoscopically. Women and older donors seemed to stand the pain better after operation. It is possible that these people were more patient, or that the judgement about the operation of the younger donors and male donors were played down.

Feelings of abandonment and exploitation were rather frequent. After having mobilized determination and anxiety defences to brave an exceptional situation, a depression-like reaction might develop, where regression is a prominent feature. In regression, there is a strong need to be cared for and get attention and love; an intensified sensitivity is common. However, after transplantation most of the interest was shifted to the recipients and to efforts of avoiding rejection of the kidney, and the recipients often were fully occupied with themselves. Thus, the donors depended on the ward staff to satisfy their regressive needs. Possibly, such needs are not observed or accepted by caregivers, who instead encourage ‘adult’ behaviour. Finally, the donors desired to be recognized for their deeds in this step when they were the weakest. There is no contra-indication, rather an indication, for the staff to act as vicarious gratitude providers. The distant attitudes of the clinics might even here depend on the ambivalence toward the whole idea of living donation. (The recipients’ ability to express their thankfulness varied a great deal. The issues of gratitude in living donation will be explored in a forthcoming article.)

Conflicts within living donation parties

Evidently, there is a paradox in mutilating a healthy person for another individual’s wellbeing. The works of, for instance, Spital [19] point to such ambivalence, even if a recent survey of US transplant centres demonstrates an increasingly positive attitude toward living donation, at least in the USA [20]. However, such ambivalence might explain why the examination
programmes sometimes seemed to be missing, and why some donors felt like pioneers in an enterprise without reliable routines. Another reason for this distancing of the donors might be the doctors’ fear of interfering in the decision of the presumptive donor. However, the donors wished to be part of a transplant programme and feel that the health care staff were keen to assist in an important issue, to support their psychological needs and even provide vicarious gratitude.

Living donation is a complex enterprise for all parties involved—the health care, the donors and the recipients—because there are always conflicting interests within these parties which should not be denied but rather discussed openly. However, these conflicts should not affect the care of the donors. There is a need for improvements in this respect, including involvement of the donors in a structured donation programme while they undergo their examinations and wait for the nephrectomy. This could be done without making them feel compelled to carry through the donation if they come to regret their promise. The ambivalence of healthcare to living donation should not fall upon the donors during a time that is stressful both for themselves and their recipients anyway.

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Appendix

Interview guide, first interview

Tell me how it happens that you are here today for donating a kidney to X. How did it all start? How were you informed that the time had come when X had to have a transplant? When did you start thinking of yourself as a possible donor? What did you know about living donation then? Were there other candidates? How did you get information? What problems did you consider? When did you decide on donation? Any external pressure? What happened next (examinations, contact with health care, problems, support)? Have you sometimes been hesitant? Feelings and thoughts on surgery?

Interview guide, second interview

How are you today? What has happened since we met before surgery? How was the operation and how did you feel afterwards? Was the pain as you expected, worse or easier? How did you perceive the pain compared with your previous experiences of pain? What about the hospital stay and the caring? Was everything OK? Any problems? How did you feel at discharge?