The kidney recipient’s path to transplantation: a comparison between living and deceased kidney donor recipients in Stockholm, Sweden

Margareta A. Sanner¹, Eva Lagging² and Annika Tibell³

¹Department of Public Health and Caring Sciences, Health Services Research, Uppsala University, Uppsala, Sweden, ²Stockholm Diabetes Association, Stockholm, Sweden and ³Department of Transplantation Surgery, Karolinska University Hospital, Huddinge, Sweden

Correspondence and offprint requests to: Margareta A. Sanner; E-mail: margareta.sanner@pubcare.uu.se

Abstract

Background. Much remains to be done to facilitate the transplantation process for patients with end-stage renal disease. The aim here was to explore these patients' experiences of the donation process and factors related to whether the actual donors of the recipients were living or deceased and describe which issues needed attention in a quality development project.

Method. A specially constructed questionnaire was sent to 246 recipients of living and deceased kidney transplants who had been transplanted at the Karolinska University Hospital in Stockholm, Sweden. The response rate was 87%.

Results. Six conditions were identified as problematic:

- Most living-donor kidney recipients perceived the evaluation period for the donors as too long.
- Although a living donor was available, most living-donor kidney recipients had to undergo dialysis for a relatively long period.
- A majority of the patients perceived it difficult to ask for a donation. Deceased-donor kidney recipients were least satisfied with the offered support in finding a living donor.
- Patients perceived fear as the main reason for potential living donors to refuse donation.
- About one-fourth of living-donor kidney recipients thought that the donors were abandoned by healthcare after nephrectomy.
- Older patients and singles were least likely to receive a living-donor kidney.

Conclusions. The problem issues outlined above should be scrutinized and improved. Checking these issues can be used in quality control when analysing living kidney donation at local and national levels.

Keywords: donation process; kidney transplant recipients; living kidney donation; quality control; transplantation

Introduction

It is well known that there is a lack of kidney transplants, and many patients with end-stage renal disease (ESRD) have to wait for transplantation for a long time. Meanwhile, they are treated with dialysis, which is an expensive treatment and mostly implies considerable restrictions on the patient’s life. There are two possibilities to receive a transplant: from a deceased or living donor. In Sweden, there are as many living kidney donors as deceased donors per year. In January 2009, 452 patients were on the waiting list for a deceased-donor kidney. During 2008, 419 ESRD patients were transplanted, 136 with a kidney from a living donor and 283 from a deceased donor.

The waiting time for kidney transplantation with a living donor is usually shorter than with a deceased donor. Moreover, the results after kidney transplantation with living donors are better than those with deceased donors, probably because the operation can be planned beforehand, meaning that both the donor and recipient are thoroughly evaluated and well prepared and the kidney can be transplanted without prolonged cold ischaemia time. Only donors who are fully healthy are accepted. A kidney from a living donor should therefore be optimal. The dialysis period can be minimized or totally eliminated. Against this background, living donation is desired. Two prerequisites for living donation are that the risks for the donors are negligible and that the decision to donate is voluntary. The perioperative mortality rate is about 0.03% and the rate of serious complications about 0.2%. Long-time morbidity seems to be low [1–7].

In 2008, the associations of kidney and diabetes patients in Greater Stockholm (Stockholm with suburbs) initiated a study on how kidney recipients experienced the circumstances around the donation in order to discuss ameliorations of the donation process. Many of the members of these associations were dissatisfied with the lack of support from healthcare personnel in finding a living donor when at the same time a living donation was highly recommended. A reference group was set up with representatives from the
patient associations and the departments of Nephrology and Transplantation in Greater Stockholm. The first author was invited to the group as research consultant.

It was the intention of the participating departments to use the study as one basis for a quality improvement project concerning living kidney transplantation.

The aim of the study was to explore kidney recipients’ own experiences of the way to transplantation, identify factors related to whether the actual donor of the recipients was living or deceased and describe which issues needed attention in a quality development project.

Materials and methods

Adult kidney recipients who had been transplanted at the Karolinska University Hospital from January 2004 to July 2008 were included in the sample. Recipients with a cancer illness in the terminal stage and recipients who could not read Swedish were excluded. In total, 246 kidney recipients were included, 147 recipients with transplants from a deceased donor (DD recipients) and 99 recipients with transplants from a living donor (LD recipients).

The questionnaire comprised 15 common questions, 8 questions that were specific for LD recipients and 4 questions specific for DD recipients. There was also space for comments on the different issues. The items were based on studies about living donors [8] and kidney recipients [9] as well as suggestions from the reference group. The questionnaire was tested in a pilot study on kidney recipients.

The survey was conducted between October 2008 and January 2009 with a first mail followed by two reminders. The answers were confidential.

The questionnaire responses were first analysed separately for the two recipient groups and these groups thereafter compared with each other through chi-square analyses. The differences between means were calculated through Student’s t-tests. Only differences significant on 5% levels or less are reported.

Results

Response rates

In total, 214 recipients, 87%, answered the questionnaire. The response rate of the LD recipients was 85% and for the DD recipients 88%.

Background factors

Female recipients were in minority both among LD and DD recipients, 30% and 41%. The DD recipients were older (53.9 ± 10.8) when transplanted at the latest occasion than the LD recipients (46.2 ± 13.4) (P = 0.0001).

There was a greater proportion of singles among the DD recipients (42%) compared with the LD recipients (27%) (P = 0.022).

Among the LD recipients, 24% had been transplanted more than once as well as 17% of the DD recipients.

A larger proportion of DD recipients had undergone dialysis before the transplantation compared with the LD recipients (P = 0.001). The range of time on dialysis was wide for both groups (Table 1), but the period of dialysis was considerably longer for the DD recipients (P = 0.0001).

Recipients who received a kidney from a living donor at the latest transplantation had more often than the others also had a living donor previously (P = 0.028). One of the LD recipients had a living donor for all her four transplantations. Five of the recipients stated that they did not know whether they received the kidney from a living or deceased donor (All these individuals were DD recipients).

Possibilities for living donation

Only 2% of the DD recipients stated that they would have declined a living donor. A total of 77% reported that they had had one or more potential living donors. However, 5% of the DD recipients mentioned that there were some potential donors that did not step forward. For 20% of the DD recipients, there was no potential living donor. The reasons why no living donation was realized, according to the DD recipients, are presented in Table 2. Ten recipients did not know why the living donation did not take place.

In the DD recipient group, 60% of the potential donors reported themselves to the patients, 27% had been requested by the patients and 13% by the patient’s doctor. The latter mostly concerned siblings and parents. Among the LD recipients, the distribution was similar (Table 3). The closest relatives were the most frequent potential donors and actual donors (Table 4).

Opinions about the donation request

Most respondents found it difficult to ask somebody to donate a kidney; the DD recipients stated this more often

<table>
<thead>
<tr>
<th>Reason</th>
<th>LD recipients</th>
<th>DD recipients</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Potential donor not healthy enough</td>
<td>46</td>
<td>34</td>
</tr>
<tr>
<td>Potential donor not suitable</td>
<td>21</td>
<td>17</td>
</tr>
<tr>
<td>There was no donor</td>
<td>16</td>
<td>12</td>
</tr>
<tr>
<td>Potential donor refused</td>
<td>14</td>
<td>10</td>
</tr>
<tr>
<td>No donor turned up</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Recipient got kidney from a deceased directly</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Recipient preferred a deceased donor</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Potential donor too young/old</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Family planning</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Other reasons</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Do not know why</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>135</td>
<td>100</td>
</tr>
</tbody>
</table>

*Patient had small children who needed at least one parent at home, so the partner was not possible as donor.

** (i) Nephrology clinic had ‘frittered away’ willing donors according to patient. (ii) Potential donor demanded unreasonable conditions for donation. (iii) Patient thought he did not deserve a living donor.
than the LD recipients (81% versus 69%) (P = 0.02). The respondents who had raised the question themselves did not differ from those who had not, in their views on the question being difficult or easy.

Concerning whether the nephrologist should be the person requesting donation, the views of the LD and DD recipients differed; 64% of the DD recipients thought this best compared with 36% of the LD recipients (P = 0.012). The comments on this question, that supported requests from the nephrologists, stressed that a physician could better explain the medical issues and circumstances around the operation, that the request appeared more serious and that the patient her/himself was too delicate and ill to try to find a donor. Comments that were negative to such a request stated that a potential donor would feel a stronger compulsion to donate if a physician asked. Some respondents thought that nobody should ask for donation; a willing donor should announce this by her/himself.

The LD recipients stated more often (80%) that they had received good enough information about living donation compared with DD recipients (63%) (P = 0.038). Moreover, the LD recipients were more satisfied with the support from the healthcare personnel to find a living donor (P = 0.018) (Table 5). However, half the respondents thought that they did not need any help or that this issue was irrelevant for them. Primarily, the LD recipients who had been offered a kidney from their partner or parents reported that they did not need any support. Those who had wanted help to find a donor wanted advice about how to bring up the request and who might be suitable to ask. Being allowed to use doctors and staff as discussion partners in this very sensitive situation seemed to be most important.

### Evaluation period of the donor

The mean time of the evaluation period was 11.0 ± 8.6 months and the range 1–48 months. The majority of the LD recipients thought that this period was too long (Table 6). They stated that the examinations were inefficient and badly coordinated, that they had to drive the project themselves, that they ‘had been lost’, that nobody seemed to be responsible and that the information about the situation had been poor.

Almost one-fourth of the respondents were dissatisfied with the way the donor had been taken care of after the donation and wanted better follow-up and contact with the physicians (Table 7). Citing one LD recipient: ‘They have made an enormous offer and they should at least be met with attention and respect. This is terribly important even for the recipients, otherwise you might regret that you accepted the offer and feel guilty.’

### Discussion

#### Sociodemographic differences

The two groups of recipients differed with regard to age and civil status; the DD recipients were older and more often singles. Both factors affect the possibility of receiving a kidney from a living donor: with higher age there is less probability to receive a kidney from parents, partners and siblings because they are more likely to be ill or even dead in comparison to younger persons. Moreover, partners comprised the largest category of donors among the LD recipients; because the DD recipients more often were singles, the number of potential donors might have been restricted. Having a large social network means a larger number of potential donors. It is probable that single and older patients would need more attention and support from healthcare personnel in finding a living donor.

The skewed sex distribution in the two recipient groups, also found in previous studies [10], is explained by the differences in ESRD frequencies between men and women. In Sweden, about 70% of those who develop ESRD are male.

#### The difficult request

The donation issue is delicate for the recipients, the nephrologists, the transplant surgeons and the nursing staff [8,9,11–13]. This is due to the risk to life and health that is always connected to large operations, the post-operative pain and the necessary sick leave and other inconveniences that the donor has to endure as well as a certain insecurity of what life with a single kidney means. A potential donor might feel guilty or be afraid of being regarded as a coward and indifferent to the suffering of a close relative if she/he declines donation. Not being offered a kidney from a close family member may lead to the patient feeling less loved and appreciated. It is essential that healthcare personnel do not bring pressure to bear on a potential donor or act in a biased way to secure a donation.

Against this background, most patients thought it difficult to ask for a donation themselves. On the other hand,
the LD recipients did not think it would be better that their doctor made the request; they wanted to take the responsibility for this themselves. However, most DD recipients preferred that the nephrologist made the request. This probably reflects that their own efforts of finding a donor were futile or that they had not dared to ask themselves.

Several DD recipients did not know why the donation from a potential donor did not take place, which is an indication of the difficulty to speak freely about the donation and the deliberations about it. Sometimes, the person who is excluded as donor may be ashamed of not being suitable or not having dared to undergo the operation and retires.

Even concerning deceased donors, the donation is sometimes surrounded by silence (cf [9]). Some of the DD recipients stated that they did not know whether their transplant came from a living or deceased donor. This was also the case in a previous interview study [8]. However, there are sometimes medical reasons for such a delay, such as keeping up to the decreasing kidney capacity of the patient with the development of the examinations in order not to have to replicate the tests when it is time for transplantation.

### The well-being of the donor

Three quarters of the DD recipients had had a potential donor without a donation being accomplished due to many reasons. Some of these reasons, listed in Table 2, can probably be modified. According to the DD recipients, the most frequent reason to exclude a potential donor was that she/he was not healthy enough. The well-being of the donor was of utmost importance for the recipients, and it seems probable that the patients had made their own selection of potential donors based on what they thought was important to medically manage a donation. This stresses the importance that the patients are well informed in these matters and can discuss them with their nephrologists and nurses.

The 14 potential donors who refused donation were said to do this due to fear. As we have no information directly from these individuals, we do not know exactly what

---

**Table 5. Recipients’ perception on support from healthcare personnel to find a living donor**

<table>
<thead>
<tr>
<th>Enough support from healthcare personnel to find a living donor</th>
<th>LD recipients (n = 83)</th>
<th>DD recipients (n = 119)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Yes</td>
<td>16</td>
<td>19</td>
</tr>
<tr>
<td>Partly</td>
<td>13</td>
<td>16</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>12</td>
</tr>
<tr>
<td>Did not need help</td>
<td>44</td>
<td>53</td>
</tr>
<tr>
<td>Support was not of interest in this case</td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
</table>

---

**Table 6. LD recipients’ perception on length of evaluation**

<table>
<thead>
<tr>
<th>LD recipients’ perception on length of evaluation</th>
<th>LD recipients (n = 82)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
</tr>
<tr>
<td>Too short</td>
<td>0</td>
</tr>
<tr>
<td>Just right</td>
<td>25</td>
</tr>
<tr>
<td>Too long</td>
<td>44</td>
</tr>
<tr>
<td>Do not know</td>
<td>13</td>
</tr>
</tbody>
</table>

---

**Table 7. LD recipients’ perception on support to the donors**

<table>
<thead>
<tr>
<th>Enough support during evaluation (n = 82)</th>
<th>Enough support after operation (n = 82)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Answer</td>
<td>n</td>
</tr>
<tr>
<td>Yes</td>
<td>58</td>
</tr>
<tr>
<td>No</td>
<td>13</td>
</tr>
<tr>
<td>Do not know</td>
<td>11</td>
</tr>
</tbody>
</table>
caused their fear about the kidney donation nor how well informed these individuals were. It is possible that they would have overcome their fear if they had had better knowledge about how a nephrectomy is performed and what it means to live with only one kidney. The information and interview with the potential donor is therefore crucial. In this context, we want to stress that an obligation to donate should never be perceived; what is essential is that the potential donor is capable of making a well informed and voluntary decision.

The donors’ need for support from healthcare staff during the evaluation period and after the operation is stressed by the donors themselves [8]. In the present study, about one-fourth of the LD recipients stated that their donors had not been attended to in the best way after operation. Because the recipients have a strong need to reciprocate the unique gift, the perception that the donors are not sufficiently cared for might be even more frustrating. Citing one LD recipient: ‘They should be treated like heroes or at least have all the caring they need afterwards.’

Conclusions

The very high response rates indicate that the kidney recipients were eager to announce their views on organ donation and transplantation. Much remains to be done to facilitate the donation process for the ESRD patients. The following conditions were identified as problem areas that should be scrutinized and improved. Checking these conditions can be used as a quality control when analysing living kidney donation at local and national levels.

- Most living-donor kidney recipients perceived the evaluation period for the donors as too long.
- Although a living donor was available, most living-donor kidney recipients had to undergo dialysis for a relatively long period.
- A majority of the patients perceived it difficult to ask for a donation. Deceased-donor kidney recipients were least satisfied with the offered support in finding a living donor.
- Patients perceived fear as the main reason for potential living donors to refuse donation.

- About one-quarter of living-donor kidney recipients thought that the donors were abandoned by healthcare after nephrectomy.
- Older patients and singles were least likely to receive a living-donor kidney.

Transparency declaration. The results presented in this paper have not been published previously in whole or part, except in abstract format.

Conflict of interest statement. None declared.

References


Received for publication: 8.12.09; Accepted in revised form: 7.7.10