The Impact of Living-Related Kidney Transplantation on the Donor’s Life

Jens Reimer,1,4 Anne Rensing,2 Christian Haasen,1 Thomas Philipp,2 Frank Pietruck,2 and Gabriele Helga Franke3

Background. Living-donation kidney transplantation (LDKT) is increasingly performed for treatment of chronic renal failure. Recently, risks for the donor and problems in decision-making have been stressed. This study was conducted to illuminate the decision-making process and consequences of LDKT on family life, the financial and occupational situation. Moreover, quality of life (QOL) and mental distress were explored.

Methods. All German residents at Essen University, who donated their kidney between 1999 and 2003, were included in the study. Donors filled out the questionnaire of the European Multicenter Study of Transplantation Using Living Donors, the Short Form 36-Health Survey, and the Brief Symptom Inventory.

Results. Out of a total of 65 donors, 47 replied (72%) at an average 2.5 years postdonation. No fatalities occurred in the whole sample (n = 65), medical complications were experienced by 28%. Most donors decided voluntarily (94%) and spontaneously (66%) to donate, after donation 96% stated that they would decide in the same way again. QOL was within the norm. On the other hand, 10% experienced family conflicts, every eighth donor suffered from clinically relevant distress, financial disadvantages were experienced by every fourth donor, with 25% not answering this question.

Conclusion. Seen from the donor’s perspective, LDKT is a relatively safe procedure. However, increased rates of donors with mental distress and intra-familial conflicts emphasize the need for a careful selection process. Regular postdonation psychosocial screening and provision of specific interventions to those in need are recommended. Donors should not suffer from financial and occupational disadvantages resulting from donation.

Keywords: Kidney transplantation, Living donor, Quality of life, Outcomes.

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Living-donor kidney transplantation (LDKT) is increasingly performed to treat end-stage renal disease (ESRD) (1). LDKT has mainly been developed to overcome shortage of kidney grafts, and leads to excellent medical results in terms of graft survival (2). Seen from the recipient’s perspective, LDKT represents a favorable approach for treatment of ESRD, whilst questions arise when taking up the donor’s position. In kidney donors the frequency of perioperative medical complications is between 3–7% with a mortality rate between 0% and 0.03% (3–7). The long-term outcome in terms of mortality is better than the expected mortality (8). Most studies rate donor’s quality of life (QOL) to be better than or equivalent to that of controls (9–12). This fact has been linked to specific personality traits with high self-esteem and positive reinforcement of this specific characteristic by donation (13).

Recently, concern has been raised about the safety of donors (14). Donors were found to be at higher risk of developing psychiatric disorder, between 1% and 5% of donors would not donate again, up to 5% suffer from long-term mental problems, up to 15% of donors believe that donating impacted negatively on their health, and between 16–23% reported of negative financial consequences (9, 13, 15, 16). Furthermore, some studies described impaired QOL in donors (15, 16). As a consequence, some authors suggested to monitor donors also in terms of postdonation psychosocial parameters and to offer counselling to those in need (12, 16).

Moreover, attention has been drawn to the process of selecting potential donors. Overt coercion to donate has only rarely been described, but unsaid coercion may be prevalent more frequently (17). Recently seven motives (e.g. identification, a desire to help, a feeling of moral duty etc.) have been identified, that may lead to the point where donation becomes the “only option”, resulting in postdonation family conflicts (18–20).

This study was initiated in the context of the responsibility that society and health care system take on beyond “normal” tasks by bringing a potentially normal person into the role of becoming a possible or real donor. The study aims to illuminate the decision-making and donation process, and to explore quality of life and mental health in living kidney donors postoperatively with standardized instruments.

MATERIALS AND METHODS

Patients

All patients, who underwent nephrectomy between 1999 and 2003 at the Transplantation Centre of the University of Essen for the purpose of LDKT, except those not resident in Germany, were included in the study. The questionnaires were sent off by postage mail. If no answer was received within one month, a second set of questionnaires was sent.
Patients who did not answer one month after the second re-
quest were contacted by telephone. If participation was re-
fused, reasons for non-participation were recorded. In-
formed consent was obtained from each study participant.
Non-participation was regarded as the patient’s legal right.

Before donation, the potential candidates (n = 138) un-
derwent a comprehensive diagnostic evaluation; besides the
physical examination, an extensive psychiatric evaluation was
conducted. Psychiatric evaluation included separate inter-
views for the donor and recipient with the psychiatrist.
Among the potential candidates, 20 were excluded from do-
nation for medical reasons (cross match positive (5), cardio-
vascular problems (3), kidney abnormalities (3), cancer
(mostly carcinoma in situ of the mamma) (4), chronic hep-
itis B (1), other reasons (4)). Four potential donors did not
qualify because of psychosocial and mental problems and two
were rejected by the ethics committee. In nineteen cases, the
potential recipient received a cadaveric kidney during the
evaluation process, and in six candidates further evaluation
was discontinued, as the potential recipient died. In eight
cases the potential donor decided not to donate through the
evaluation process, in seven cases the donation process was
postponed, two donor/recipient-pairs moved, and in five
cases the evaluation process was still ongoing during the study
period.

Eurotold Questionnaire

The questionnaire of the European Multicenter Study
of Transplantation Using Living Donors (EUROTOLD) was
administered to gain sociodemographic and donation-asso-
ciated data. The questionnaire covers the following topics:
Demographic data: age, gender, marital status, profes-
sion, relationship to recipient.
Medical and psychosomatic data.
Duration of hospital stay, physical and mental prob-
lems due to the operation / donation. Changes in self-esteem
through LDKT.

Decision to Donate

Did the donation cause any family conflicts and did the
family status change after donation? Were there other poten-
tial donors in the family? From which source did the donor
find out about the possibility of LDKT and who asked the
donor to donate? Was the decision spontaneous? Have there
been doubts or family conflicts during the decision-making
process and at what time was the decision finally made? How
was the degree of information concerning medical risks at the
time of decision and how difficult was the decision to donate?
Which were the main worries before transplantation? After
the donation, would the donor decide in the same way again,
did the regard of LDKT change, and was the risk of operation
estimated differently after the transplantation?

Vocational Situation and Financial Aspects

Did any problems occur at work or with the employer
before and after donation? How long did it take to recover
from the operation and when did the donor start to work
again after the donation? Were there any financial problems
due to the donation and was there any kind of compensation?

QOL Questionnaire

Global QOL was measured by the SF-36, which has
been proven to be an adequate instrument for organ donors
(12, 17). The SF-36 comprises 36 items, which constitute
eight subscales and two sum scores. The subscales comprise
1) "Physical Functioning," 2) "Role Physical," 3) "Bodily
Pain," 4) "General Health," 5) "Vitality," 6) "Social Function-
ing," 7) "Role Emotional," and 8) "Mental Health." Scales
1– 4 contribute to the scoring of the "Physical Component
Summary," whereas scales 5– 8 contribute to the scoring of
the "Mental Component Summary." Psychometric proper-
ties of the SF-36 in German samples met the standard require-
ments in terms of internal consistency, convergent and dis-
criminant validity, and sensitivity. In a German norm
population (n = 2914), Cronbach’s α was between 0.57 and
0.93, with four coefficients out of 48 not reaching 0.7 (21–23).

Mental Distress Questionnaire

Special attention was drawn to the detection of mental
distress using the Brief Symptom Inventory (24). The BSI
contains 53 items, which constitute nine subscales and three
global scores. The subscales include “Somatization,” “Obses-
sive-Compulsive,” “Interpersonal Sensitivity,” “Depression,”
“Anxiety,” “Anger/Hostility,” “Phobic Anxiety,” “Paranoid
Ideation,” and “Psychoticism.” The three global indices re-
fect various aspects of overall mental distress: GSI (Global
Severity Index), PSDI (Positive Symptom Distress Index),
and PST (Positive Symptom Total). Psychometric properties
of the BSI have proven to be adequate in terms of convergent
and discriminant validity, sensitivity and reliability in a Ger-
mern population (n = 600) (24). In end-stage renal-dise-
ase patients, Cronbach’s α was between 0.63 and 0.85 with
two coefficients out of ten not reaching 0.7 (25). Clinically
relevant mental distress is diagnosed if the criteria of the
“case-definition” (Global Severity Index and/or two subscales
with a T-score ≥ 63) are met (26).

Statistics

Analyses were performed using the SPSS computer
package (version 10.1, SPSS Inc. Chicago, Illinois). Compar-
isons between donors and the population norm (SF-36) were
conducted by a two-tailed t test. Differences were regarded as
statistically significant in case P < 0.05, precepts for multiple
testing were considered. Additionally effect sizes were com-
puted to allow for consideration of clinical relevance (27).

RESULTS

Donors

Of a total of 65 donors, 47 replied (72.3%). Question-
naires were completed at home and sent back to the Depart-
ment of Nephrology; none of the questionnaires were an-
swered via telephone. Of the 18 non-repliers, ten had moved
and could not be contacted, six were suspicious against psy-
chological investigations, and two experienced an adverse
outcome of donation (mental disorder / weakness of the ab-
dominal wall respectively), and thus refused participation.
Among the 47 donors there were 16 men (34%) and 31
women (66%); mean age was 53.5 years (± 9.6). Mean time
between donation and participation in the study was 31
months (± 14) (Table 1).

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Medical Data

The mean hospital stay was 8.8 days (±1.2). Eighteen donors (38.3%) experienced medical complications postoperatively; complications were classified as slight in 14 cases (19.8%), as medium in one case (2.1%), as severe in three cases (6.4%), none rated the complications as very severe. In detail, 14 donors suffered from pain and cicatrice problems, each one suffered from weakness of the tissue next to the cicatrice, from reduced resilience and one donor was subject to chronic renal dialysis after renal failure due to hemorrhagic hypovolemia.

Recipients

The mean recipient age was 33.5 (±19.2) years; there were 27 men (57.4%) and 20 women (43.6%). Recipients were related to the donor as follows: father (2 cases), mother (2), brother (3), sister (3), daughter (15), wife (7), husband (7), other (nephew, son in law etc.; 5). At the time of the survey, all recipients lived with a functioning graft. The state of health of the recipients was classified by the donor as follows; excellent in 17 cases (36%), good in 25 cases (53%), medium in three cases (7%) and moderate in two cases (4%).

Family Problems

The family situation changed in five cases (10.6%) after the donation, one donor got married, another donor started a new partnership, and three donors separated from their partners. The donation led to family conflicts in five cases, which were classified as slight conflicts in four cases and as medium conflict in one case.

Decision-making Process

Most donors (26/47) learned from the media about the possibility of performing a LDKT, others were informed by the dialysis physician (6) or the recipients General Practitioner (1), from other physicians (8), from the recipient (4) or relatives (2). The vast majority disclosed their wish to donate without being asked (43/47), four were asked by others. In about every third case (31.9%), other potential donors entered the process of medical and psychiatric evaluation as well. The decision to donate was made by 2/3 of the donors (31/47) immediately after they had learned about the possibility of LDKT. Five donors made up their mind after discussing the issue with a physician, each three donors decided in favor of donation either after completion of the evaluation process, or after discussion with a close friend/relative, or after discussion with the recipient. In two cases, the decision was made after a non-disclosed process. The decision-making process was described as easy by three out of four donors (35/47), nine donors rated the process as not very difficult, one as medium difficult, and two as difficult. None rated the decision-making process as very difficult (Fig. 1).

Most donors did not feel pressured at all (44/47) or had any kind of doubts (43/47) about undergoing the donation. Two donors reported slight pressure and one donor medium pressure through the decision-making process; each one felt coerced by family members, or medical staff, or one’s consciousness. Four donors reported slight doubts with respect to the donation.

At the time of decision, donors were already well informed about risks of undergoing LDKT, every second donor felt very well informed (23/47), and nearly every third donor felt well informed (14/47).

Donors were asked to identify their worries before undergoing the operation. A large number of donors (40/47) were worried about the possibility of graft failure (85%). Each

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**TABLE 1.** Sociodemographic characteristics of kidney donors

<table>
<thead>
<tr>
<th>Characteristic</th>
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<tbody>
<tr>
<td>Sex (female/male)</td>
<td>16/31</td>
</tr>
<tr>
<td>Age at study (years)</td>
<td>53.6±9.6 (31–74)</td>
</tr>
<tr>
<td>Age at donation (years)</td>
<td>50.8±9.7 (28–71)</td>
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<tr>
<td>Familial situation</td>
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<tr>
<td>Married</td>
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<tr>
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<td>13 years</td>
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**FIGURE 1.** How difficult was the decision to donate for you?

**FIGURE 2.** How did you estimate the risk of the donation right before the operation (Pre)? How did you estimate the risk of donation right now (Post)?

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**Family Problems**

The family situation changed in five cases (10.6%) after the donation, one donor got married, another donor started a new partnership, and three donors separated from their partners. The donation led to family conflicts in five cases, which were classified as slight conflicts in four cases and as medium conflict in one case.

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Most donors (26/47) learned from the media about the possibility of performing a LDKT, others were informed by the dialysis physician (6) or the recipients General Practitioner (1), from other physicians (8), from the recipient (4) or relatives (2). The vast majority disclosed their wish to donate without being asked (43/47), four were asked by others. In about every third case (31.9%), other potential donors entered the process of medical and psychiatric evaluation as well. The decision to donate was made by 2/3 of the donors (31/47) immediately after they had learned about the possibility of LDKT. Five donors made up their mind after discussing the issue with a physician, each three donors decided in favor of donation either after completion of the evaluation process, or after discussion with a close friend/relative, or after discussion with the recipient. In two cases, the decision was made after a non-disclosed process. The decision-making process was described as easy by three out of four donors (35/47), nine donors rated the process as not very difficult, one as medium difficult, and two as difficult. None rated the decision-making process as very difficult (Fig. 1).

Most donors did not feel pressured at all (44/47) or had any kind of doubts (43/47) about undergoing the donation. Two donors reported slight pressure and one donor medium pressure through the decision-making process; each one felt coerced by family members, or medical staff, or one’s consciousness. Four donors reported slight doubts with respect to the donation.

At the time of decision, donors were already well informed about risks of undergoing LDKT, every second donor felt very well informed (23/47), and nearly every third donor felt well informed (14/47).

Donors were asked to identify their worries before undergoing the operation. A large number of donors (40/47) were worried about the possibility of graft failure (85%). Each
When regarding the subscales, global QOL was statistically
scored as very high by none (one) (Fig. 2).

Three donors were concerned about potential negative conse-
quences within their family or about mutual health hazards, one
was afraid of the operation risk. None reported worries about
mutual negative financial consequences.

Retrospectively, all but two donors (96%) would decide
for LDKT again. Self-esteem improved through LDKT in ev-
ey third donor (14/47) and remained stable in the remaining
donors. One donor reported strong mental problems after
donation (worries about the remaining kidney), two donors
reported slight mental problems; the vast majority (44/47)
did not express concern about mental problems. The medical
risk of undergoing LDKT was rated as marginal by 13 donors
before donation (16 after donation), as low by 25 donors (25),
as medium by eight donors (five), as high by one donor (nil),
and as very high by none (one) (Fig. 2).

Financial and Occupational Issues

Twenty-six of the employed donors (n=32) did not experience
any problems with their employer as a result of the
temporary interruption of work before and after donation.
Four donors reported slight, one medium, and one very
strong problems which were not further specified. On aver-
age, donors returned to work after 7 weeks (±6.7) and felt
fully recovered in their capacity to work after 13 weeks
(±13.3). Four donors each experienced no physical distress at
work preoperatively and postoperatively, the corresponding
numbers for slight physical distress were 6 and 4, medium
physical distress 15 and 14, strong physical distress 7 and 4,
and very strong physical distress 4 and 3. Eleven donors did
not answer to this question preoperatively and 14 postopera-
tively. Postdonation, donors in general did not suffer from
any problems with their employer as a result of the
EUROTOLD questionnaire, in most cases the decision
during nephrectomy. From the declaration of the donors in
the whole cohort of donors (n=65) studied, in those responding (n=47) severe or med-
dium peri- or postoperative medical complications occurred
with a frequency of less than 10%. However, one donor was
subject to chronic dialysis due to hemorrhagic hypovolemia
during nephrectomy. From the declaration of the donors in
the EUROTOP questionnaire, in most cases the decision
was made easily, spontaneously without being asked, and vol-
untarily. Postdonation, donors in general did not suffer from
relevant mental distress (BSI). The donors’ QOL (SF-36) is
generally comparable to the population norm with some dif-
erential distinctions, which are, however, of low effect sizes
significantly impaired in the kidney donors in the areas
“Physical Function” (P<0.001; effect size d=0.10) and “Role
Emotional” (P<0.0001; d=0.13), whereas the donors scored
statistically significantly higher in the areas “General Health”
(d=0.14), “Vitality” (d=0.15), and “Mental Health”
(d=0.12) (all P<0.0001) as compared to the norm popula-
tion (Fig. 4).

Mental Distress

In general, donors were not mentally distressed; all av-
erage values of the BSI subscales and global indices were
within the normal range. However, six patients met the crite-
ria of the “case-definition”, which indicates existence of rele-
vant mental distress. Scales with a T-score (scores ranging
from 20–80, with 80 indicating maximum mental distress) of
≥60 (one standard deviation above the norm) included
“Anxiety” (T=69), “Somatization” (T=67), “Psychoticism”
(T=66), “Paranoid Ideation” (T=63), “Depression”
(T=62), “Obsessive-Compulsive” (T=62), and “Interper-
sonal Sensitivity” (T=60). On a single-item level, the items
“Nervousness or shakiness inside,” “Terror or panic attacks,”
“Hot and/or cold flushes,” “Numbness or jimmies in parts of
the body,” “Trouble falling asleep,” “The feeling others are to
blame for most of your troubles,” and “Feeling lonely” scored
highest.

DISCUSSION

No fatalities occurred in the whole cohort of donors
(n=65) studied, in those responding (n=47) severe or med-
dium peri- or postoperative medical complications occurred
with a frequency of less than 10%. However, one donor was
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QOL

The sum scores (Physical Component Summary, T-score=50.1±9.6; and Mental Component Summary, T-
score=52±10.3) did not differ from the population norm.
When regarding the subscales, global QOL was statistically

![FIGURE 3. Did you experience physical distress at work preoperatively (Pre) / postoperatively (Post)?](image)

![FIGURE 4. QOL in kidney donors compared to the norm population.](image)
and of limited clinical relevance (27–29). Focusing these facts, LDKT seems to be a rather unproblematic procedure.

On the other hand, questionnaires were not sent back by one out of four donors. The majority of those had moved and could thus not be contacted, which might not bias results, but six of the 18 non-repliers were suspicious against psychological investigations and two experienced an adverse outcome of the donation (mental disorder/weakness of the abdominal wall). In the latter groups a higher number of donors experiencing adverse effects through donation may be expected.

In five cases donation led to family conflicts, and three donors felt coerced to donate. Nearly every fifth of the working donors experienced problems at work due to the donation. Donors returned to work on average seven weeks after donation, though they felt recovered not until after an average of 13 weeks. Every fourth donor sustained financial disadvantages. Moreover, every eighth donor suffered from clinically relevant mental distress.

Besides mentioned overt conflicts, non-disclosed conflicts through the decision-making process have to be assumed. Donating one’s kidney is a big gift, raising worries and (unexpressed) expectations. Previously, motives (e.g. identification, a desire to help, a feeling of moral duty etc.) have been identified that lead to the perception of donating as being the “only option”, which consequently induce a semantic shift in the meaning of the term of voluntary (donation) and spontaneous (decision) (19).

It is therefore advocated to perform a careful psychological and psychiatric pretransplant evaluation of all potential donors and also focus on aspects arguing against donation (e.g. graft failure, complications of the operation, unexpressed expectations towards the recipient, other treatment options, coercion) (19, 30). Fortunately, pressure of time in ESRD is limited due to other treatment options, which may allow to prescribe a moratorium to relax and clarify a complicated situation (20). In this context, it is also the duty of clinicians to explore the donor’s aims rather than merely discussing risks and benefits. Clinicians can then be led by what the patients want, rather than by professional assumptions about management of a disease. In return, patient satisfaction is likely to increase (31).

In our cohort, 2.5 years postdonation one out of eight donors reported clinically relevant mental distress, and in general QOL was impaired in the areas “Role Emotional” (problems with work or other daily activities as a result of emotional problems and limited in 13 weeks. Every fourth donor sustained financial disadvantages. Moreover, every eighth donor suffered from clinically relevant mental distress.

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It is therefore advocated to perform a careful psychological and psychiatric pretransplant evaluation of all potential donors and also focus on aspects arguing against donation (e.g. graft failure, complications of the operation, unexpressed expectations towards the recipient, other treatment options, coercion) (19, 30). Fortunately, pressure of time in ESRD is limited due to other treatment options, which may allow to prescribe a moratorium to relax and clarify a complicated situation (20). In this context, it is also the duty of clinicians to explore the donor’s aims rather than merely discussing risks and benefits. Clinicians can then be led by what the patients want, rather than by professional assumptions about management of a disease. In return, patient satisfaction is likely to increase (31).

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