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

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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 8–25 % 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.

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Patients who did not answer one month after the second request were contacted by telephone. If participation was refused, reasons for non-participation were recorded. Informed consent was obtained from each study participant. Non-participation was regarded as the patient's legal right.

Before donation, the potential candidates (n=138) underwent a comprehensive diagnostic evaluation; besides the physical examination, an extensive psychiatric evaluation was conducted. Psychiatric evaluation included separate interviews for the donor and recipient with the psychiatrist. Among the potential candidates, 20 were excluded from donation for medical reasons (cross match positive (*5*), cardiovascular problems (*3*), kidney abnormalities (*3*), cancer (mostly carcinoma in situ of the mamma) (*4*), chronic hepatitis 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-associated data. The questionnaire covers the following topics:

Demographic data: age, gender, marital status, profession, relationship to recipient.

Medical and psychosomatic data.

Duration of hospital stay, physical and mental problems 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 potential 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 Functioning," 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 properties of the SF-36 in German samples met the standard requirements in terms of internal consistency, convergent and discriminant 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," "Obsessive-Compulsive," "Interpersonal Sensitivity," "Depression," "Anxiety," "Anger/Hostility," "Phobic Anxiety," "Paranoid Ideation," and "Psychoticism." The three global indices reflect 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 German norm population (n=600) (*24*). In end-stage renal-disease 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 $\geq$ 63) are met (*26*).

Statistics

Analyses were performed using the SPSS computer package (version 10.1, SPSS Inc. Chicago, Illinois). Comparisons 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 computed to allow for consideration of clinical relevance (*27*).

RESULTS

Donors

Of a total of 65 donors, 47 replied (72.3%). Questionnaires were completed at home and sent back to the Department of Nephrology; none of the questionnaires were answered via telephone. Of the 18 non-repliers, ten had moved and could not be contacted, six were suspicious against psychological investigations, and two experienced an adverse outcome of donation (mental disorder / weakness of the abdominal 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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TABLE 1. Sociodemographic characteristics of kidney donors

Characteristic	Data
Sex (female/male)	16/31
Age at study (years)	53.6±9.6 (31–74)
Age at donation (years)	50.8±9.7 (28–71)
Familial situation	
Married	37 (87.7%)
Widowed	2 (4.3%)
Divorced/separated	8 (17%)
Education	
10 years	36 (76.6%)
13 years	4 (8.5%)
University degree	8 (17%)
Vocational situation	
Working full-time	18 (38.3%)
Working part-time	10 (21.3%)
Stay-at-home parent	8 (17%)
Unemployed	1 (2.1%)
Chronically ill (>1 month)	2 (4.3%)

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%).

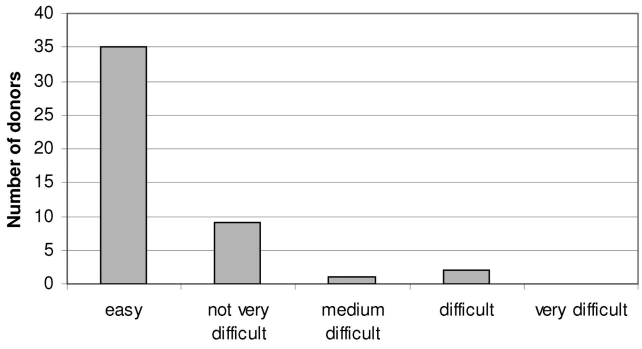

FIGURE 1. How difficult was the decision to donate for you?

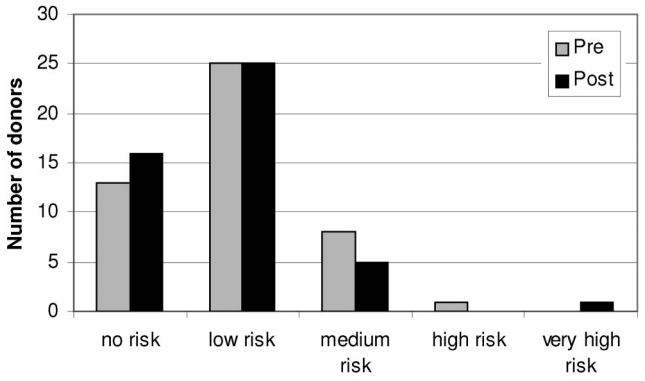

FIGURE 2. How did you estimate the risk of the donation right before the operation (Pre)? How did you estimate the risk of donation right now (Post)?

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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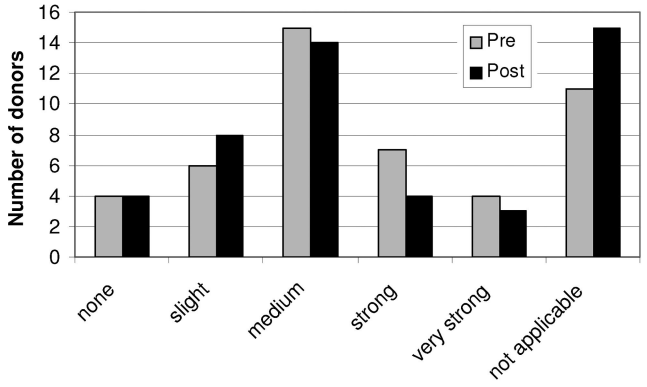


FIGURE 3. Did you experience physical distress at work preoperatively (Pre) / postoperatively (Post)?

three donors were concerned about potential negative consequences 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 every 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 average, 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 postoperatively (Fig. 3).

Donors were asked if they experienced financial disadvantages due to the donation. Nine donors refused to answer this question, of the remaining donors (n=38), one out of four had financial disadvantages (10/38). These disadvantages were compensated in one case by relatives, in the other cases no compensation was received.

QOL

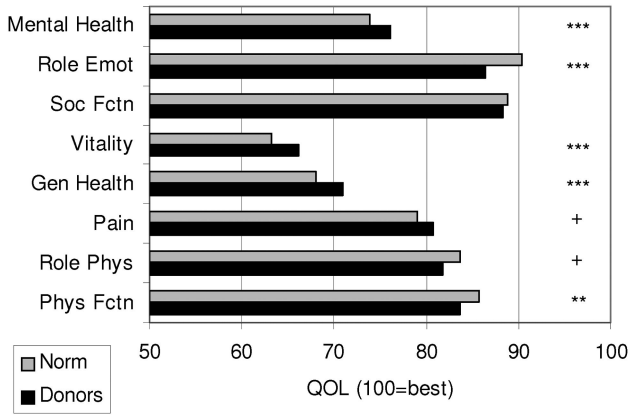
The sum scores (Physical Component Summary, T-score=50.1±9.6; and Mental Component Summary, T-score=52±10.3) did not differ from the population norm. When regarding the subscales, global QOL was statistically significantly impaired in the kidney donors in the areas "Physical Function" ($P<0.001$; effect 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 population (Fig. 4).

Mental Distress

In general, donors were not mentally distressed; all average values of the BSI subscales and global indices were within the normal range. However, six patients met the criteria of the "case-definition", which indicates existence of relevant 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 "Interpersonal 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 jimjams 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 medium 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 EUROTOLD questionnaire, in most cases the decision was made easily, spontaneously without being asked, and voluntarily. 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 differential distinctions, which are, however, of low effect sizes



Bonferroni-adjusted alpha error <.00625, +=p<.05; **=p<.001; ***=p<.0001

FIGURE 4. QOL in kidney donors compared to the norm population.

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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 psychosocial 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 "Physical Function" (limited in performing all physical activities, e.g. shopping, climbing stairs, because of health). Mental health has rarely been studied in kidney donors, and existence of clinically relevant mental distress has both been asserted and denied (*15*, *32*). From these studies and our data it seems that especially during the first year postdonation and to a lesser extent the following four years donors are at risk for developing clinically relevant distress, which tends to be marginal 10 years postdonation. Time-related data from our sample should, however be interpreted cautiously due to the relatively low number of donors who span over four years. In accordance with other studies, QOL in our sample generally is comparable to the population norm (*9–12*). Again, there seems to be a time effect, with more pronounced QOL-impairment short term after donation (*15*). It is therefore suggested to screen kidney donors for clinically relevant mental distress and QOL-impairments regularly after donation by administering standardized instruments. Intervals should be more frequently in the early postdonation phase (e.g. every four to six months). Corresponding to graft recipients, donors in need may profit from specifically designed psychosocial interventions (*33*). Specific issues to be addressed in mentally distressed donors may cover anxiety and somatic problems. More general issues relevant to donors may include problems with work or other daily activities as a result of emotional problems and limitations in performing physical activities like shopping or climbing stairs. Overall, the frequency of donors with relevant mental distress is at the lower end compared to non-clinical samples which were otherwise defined as healthy (*34*). Therefore, postoperative care of the donor should, however, be performed in a delicate balance of offering any necessary help and not making a new patient with unnecessary long term controls.

In our sample, economic losses resulting from the donation process were experienced by 25% of donors, around 20% refused to answer this delicate question. Moreover, donors felt urged to start work before feeling fully rehabilitated. Despite compensation of transplantation-associated medical costs by the recipient's insurance company, coverage of immediate harm due to the surgical procedure by a governmental accident insurance, and wage continuation, a relevant number of donors suffers from financial disadvantages and resumes work untimely. It seems inadequate that a person who saves society an average of approximately $1 million, cannot be compensated for losses of income and cannot lawfully be given the time of rehabilitation needed (*13*).

Overall, this study confirms that LDKT is seen as a relatively safe and satisfactory procedure by donors; and 96% would decide in favor of donation again. Specific problems like unsaid coercion and intra-family conflicts should be a subject of future investigations. Donors should not suffer from financial and occupational disadvantages through donation.

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