

Quality of Life of Living Kidney Donors in Germany: A Survey with the Validated Short Form-36 and Giessen Subjective Complaints List-24 Questionnaires

Markus Giessing,^{1,6} Stefan Reuter,² Bernd Schönberger,¹ Serdar Deger,¹ Ingolf Tuerk,³ Ingrid Hirte,⁴ K. Budde,⁵ L. Fritsche,⁵ Stanislao Morgera,⁵ H. H. Neumayer,⁵ and S. A. Loening¹

Background. Most studies evaluating the impact of kidney donation on donors' quality of life (QOL) have limitations such as small cohort size, unmatched references, use of nonstandardized and nonvalidated questionnaires, or low response rates.

Methods. We performed a study on donors' QOL that was designed to avoid these limitations. All available living renal donors in our department in the last 18 years were included in the study. QOL was assessed with two validated, standardized questionnaires (Short Form-36, Giessen Subjective Complaints List [Giessener Beschwerdebogen]-24) and compared with gender- and age-matched references. In addition, specific questions relating to kidney donation were asked.

Results. The response rate (89.8%) is one of the highest reported for studies on QOL of living kidney donors. Most donors had an equal or better QOL than the healthy population. Donors' willingness to donate again (93.4%) or recommend living-donor kidney transplantation (92.4%) was high, irrespective of complications. A small number of donors experienced financial drawbacks or occupational disadvantages. Donors aged 31 to 40 years were found to be at risk of QOL deterioration after organ donation. Donor and recipient complications had a significant impact on donors' QOL. One third of the donors found that the psychologic care preceding and after kidney donation was insufficient.

Conclusions. Our findings support the practice of living-donor kidney transplantation as a good means to meet the persisting organ shortage. Further effort must be put into minimizing donor and recipient complications. The specific demands of younger donors should be further elucidated. In addition to medical follow-up, living kidney donors should also be offered lifelong psychologic counseling.

Keywords: Quality of life, living kidney donors, SF 36.

(*Transplantation* 2004;78: 864–872)

Living-donor kidney transplantation (LDKT) has been encouraged and increasingly performed because of its excellent results and the persistent lack of cadaveric donor organs. Today, there are already more living than cadaveric kidney donors in the United States, and proportions are increasing in Europe as well (1, 2). Positive aspects for the donor have been described, including a timely identification of occult medical problems because of the extensive preoperative medical workup and postoperative follow-up (3–5). Numerous studies on the physical impact of organ donation suggest that kidney donation does not put the donor at an increased risk of deteriorated renal function or clinically relevant consequences such as arterial hypertension or proteinuria (6–11).

Psychosocial assessment of kidney donors is not the

standard yet, even though studies on donors' psychologic well-being and quality of life (QOL) have been conducted since the early years of LDKT (12, 13). Most studies revealed that donors often experience an increased self-esteem and a warmer and closer relationship with the recipient after organ donation (3–5, 12–14). Yet, studies often had several limitations: The QOL of renal donors was compared without matching the references for age or gender (3, 15, 16), standardized and validated questionnaires were not used (4, 17), the findings were compared with references who were validated only for another cultural background (15, 18), and the studies involved too few participants (16) or had low response rates in the range of 38% to 67% (3, 15, 17). Only one study did not have limitations (12). Nevertheless, it included donors only until 1995 and referred to Swedish donors only.

Because LDKT has been performed in our department for 20 years and studies on kidney donors QOL in Germany are lacking, we initiated a study to avoid the previously mentioned limitations. Approval for the study was obtained from the institutional review board.

PATIENTS AND METHODS

Preceding kidney explantation (until 1999 by open operation, 1999 to the present by laparoscopic procedures), all donors received a thorough medical workup. Since the implementation of the first German transplantation law in 1997, the psychologic evaluation has been performed by a psychologist (I.H.); before this, the evaluation was performed by a

M.G. and S.R. contributed equally to the article.

¹ Department of Urology, Charité University Hospital, Campus Mitte, Berlin, Germany.

² Department of Urology, Klinikum der Hansestadt Stralsund, Germany.

³ Department of Minimal Invasive Laparoscopic Urology, Lahey Clinic Medical Centre, Burlington, Massachusetts.

⁴ Institute of Medical Psychology, Charité University Hospital, Berlin, Germany.

⁵ Department of Nephrology, Charité University Hospital, Campus Mitte, Berlin, Germany.

⁶ Address correspondence to: Markus Giessing, FEBU, Klinik für Urologie, Charité Universitätsmedizin Berlin, Campus Mitte, Schumannstrasse 20–21, D-10098 Berlin, Germany. E-mail: markus.giessing@charite.de

Received 15 February 2004. Revised 11 March 2004. Accepted 17 March 2004.

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ISSN 0041-1337/04/7806-864

DOI: 10.1097/01.TP.0000133307.00604.86

team of urologists and nephrologists. Also, since 1997 ethics commission also is requested by law to state that donation is performed by free will and unpaid for. Postoperative follow-up was performed by our nephrologic outpatient department or by other outpatient services. Between January 1983 and December 2001, 120 donor nephrectomies were performed in our hospital. Two donors could not be included for reasons unrelated to organ donation (one died of bronchial carcinoma 9 years after donation; one demonstrated cerebral bleeding 4 years after donation). Twelve donors were lost to follow-up, of whom nine had donated a kidney 10 or more years ago.

Three questionnaires (Short Form [SF]-36, Giessen Subjective Complaints List [Giessener Beschwerdebogen] 24, specific questions) were sent in March 2002 to all 106 donors who could be contacted, with a follow-up of at least 1 year. Four weeks later, approximately 50% of the donors had returned the questionnaires. If no answer was returned, we called the donor, motivated him or her for participation, and sent the questionnaires again if requested. If the donor could not be contacted, we talked to the donor's doctor, the recipient, or the recipient's nephrologist and asked for assistance. Thus, by the end of 2002 we had received answers from all 106 donors who could be contacted.

Short Form-36 Questionnaire

We chose the internationally validated SF-36 questionnaire to compare our findings with others (3, 15, 16). The SF-36 is a standardized instrument for measuring QOL on eight different scales: general health perception, social function, vitality, bodily pain, physical role, physical function, mental health, and emotional role. Thirty-six questions (2–10 for each item) have to be answered, and a score is computed for each scale, ranging from 0 (least well-being) to 100 (greatest well-being) (Table 1). The questionnaire is intended for subjects aged 14 years and more, and normal values are provided referring to gender and age. In Germany, a random sample of 2,914 subjects aged more than 14 years and living in private households was chosen by two duplicate random tests from the general East and West German population to serve as reference for standardization. Scores for the individual

items differed between the East and West German references. Therefore, for statistical reasons, we noted the subjects' place of residence. The estimated time for completion of the questionnaire is 10 min (19–21).

Giessen Subjective Complaints List-24 Questionnaire

The GBB-24 (Giessen Subjective Complaints List [Giessener Beschwerdebogen]) is standardized and validated for Germany. It assesses physical complaints attributable to psychosomatic reasons (22, 23). The questionnaire has six questions, each referring to four items (cardiac complaints, gastric complaints, limb pain, fatigue tendency) for which participants are asked to rate their complaints (0=no complaints, 4=strong complaints). The sum of these four items (0–24 points) reflects the fifth item, "overall subjective complaints" (0–96 points). Findings are compared with the scores of the German references (1,601 persons) in a gender- and age-specific match, identifying the share (%) of the references with the same or fewer complaints (=feeling the same or better). To facilitate interpretation, study subjects are assigned quartiles (Q) for the respective items (Q1=0%–25%, Q2=26%–50%, Q3=51%–75%, Q4=76%–100%). Ranking of a donor in the first quartile (Q1) indicates less complaints than the controls. Q2 and Q3 reflect the range of the normal population with slightly less (Q2) or more (Q3) complaints. Q4 reflects more psychosomatic reasons for physical complaints than in the healthy population. The questionnaire is intended for subjects aged 18 years and more. The estimated time for the completion of the GBB-24 questionnaire is 10 min.

Additional Questions

This questionnaire (appendix 1) was developed in cooperation with the participating psychologist (I.H.) and consists of 20 questions regarding four topics: source of information about LDKT, influence of organ donation on psychologic and physical aspects, impact on social life, work and finances, and attitude toward LDKT. The estimated time for completion of this questionnaire was 10 to 15 min.

TABLE 1. Description of the Short Form-36 health status scales and interpretation of high and low scores

	Low score	High score
General health perception	Evaluates personal health as poor and believes it is likely to get worse	Evaluates personal health as excellent
Social function	Extreme and frequent interference with normal social activities because of physical or emotional problems	Performs normal social activities without interference from physical or emotional problems
Vitality	Feels tired and worn out all the time	Feels full of energy all the time
Bodily pain	Very severe and extremely limiting pain	No pain or no limitation as a result of pain
Physical role	Problems with work or other daily activities as a result of physical health	No problems with work or other daily activities as a result of physical health
Physical function	Limited in performing all physical activities including bathing or dressing, because of health	Performing all types of physical activities, including the most vigorous, without limitations caused by health
Mental health	Feels nervous and depressed all the time	Feels peaceful, happy, and calm all the time
Emotional role	Problems with work or other daily activities as a result of emotional problems	No problems with work or other daily activities

Statistical Analysis

Statistical analysis was performed with the commercially available SPSS 11.0 (SPSS Inc., Chicago, IL) in cooperation with the Institute of Biometrics of the Humboldt University, Berlin. Categorical parameters were compared by chi-square testing, and continuous variables were compared by the Mann-Whitney *U* test. A *P* value less than 0.05 was considered significant.

RESULTS

Of all 118 donors who were capable of answering, 106 responded, which constitutes a response rate of 89.8%. A total of 98 had donated a kidney for a first transplantation, seven for a second transplantation, and one for a third kidney transplantation. The majority of the donors (76) were related: parents (49), siblings (24), children (2), and cousin (1). Thirty donors were genetically unrelated: spouse or partner (25), friend (2), godmother/mother (1), and in-law/sister-in-law. At the time of the study, 93.4% of the recipients were alive; 91% of these had a functioning graft, and nine recipients had resumed dialysis. Overall, 38 complications occurred in 16 donors (15%), with 9 of them graded as severe (Table 2).

Short Form-36 Questionnaire

A total of 105 donors completed the SF-36 questionnaire correctly. For three items, kidney donors had a significantly better score than references. For another four items, donors scored better than references, but the differences were

not significant (Figs. 1 and 2). The score for "emotional role" was worse for the study population than for references, but the difference was not significant (Figs. 1 and 2).

The postoperative complication rate could be identified as the only difference; the donor scoring was better than control scoring. Donors with postoperative complications had worse scores on all SF-36 items. The significance level was reached for "physical functioning," "social functioning," "emotional role," and "mental health." Also, donors whose recipient had faced a complication (deceased or back on dialysis) scored worse for all items except for "physical functioning," with significantly worse QOL for the items "vitality," "social functioning," and "bodily pain."

When analyzed by decade in terms of age at the time of the study (21–30 years [*n*=2], 31–40 years [*n*=12], 41–50 years [*n*=26], 51–60 years [*n*=40], >61 years [*n*=25]), almost all donors scored better than references in almost all age groups and on almost all items. With increasing age, a level of significance was reached for an increasing number of SF-36 items (Fig. 2). Donors aged 31 to 40 years at the time of the study (mean age at donation 33 years) constituted a specific subgroup. Their scores were worse for all eight items compared with the references, but differences were significant only for the items "bodily pain" and "vitality." A closer look at potential bias in this age group revealed no statistically significant difference when scores for the items were compared with the other age groups or even the two best age groups (51–60 years and ≥60 years). We performed additional telephone interviews with the 12 donors of this group. Primarily, donors were not the major wage earner in the family and thus not under pressure because of the operation, received good social support from their families or the recipient, and mentioned no emotionally negative situation at the time of the study. One donor (5 years after organ donation) demonstrated breast cancer at the time of the study, and one donor had recently been divorced from the recipient. Even when these two donors were excluded from statistics, the donors aged 31 to 40 years showed worse scores compared with references.

When analyzed according to gender, male donors had better scores than the references for six of eight items, but they scored significantly higher only for the item "general health."

TABLE 2. Demographic data of donors and recipients and postoperative course (multiple complications in 7 of the 16 patients)

Donor gender	72 F/34 M
Donor age at donation (yr)	45.8±10.8 (19–67)
Donor age at study (yr)	52.6±10.3 (28–71)
Recipient gender	36 F/70 M
Recipient age (yr)	34.8±15.5 (5–66)
Related/unrelated	76/30
Time in hospital (days)	17.7±8.8 (7–44)
Median follow-up (mo)	75.3±66 (12–226)
Recipient complications	16
Recipient dialysis	9
Recipient death	7
Donor complications	38
Severe complications	9
Revision because of bleeding	5
Conversion because of bleeding	1
Pneumonia	2
Pancreatitis	1
Minor/moderate complications	29
Impaired wound healing	13
Hernia	11
Bleeding (conservative management)	3
Abdominal wall muscle paralysis	1
Infected lymphocele	1

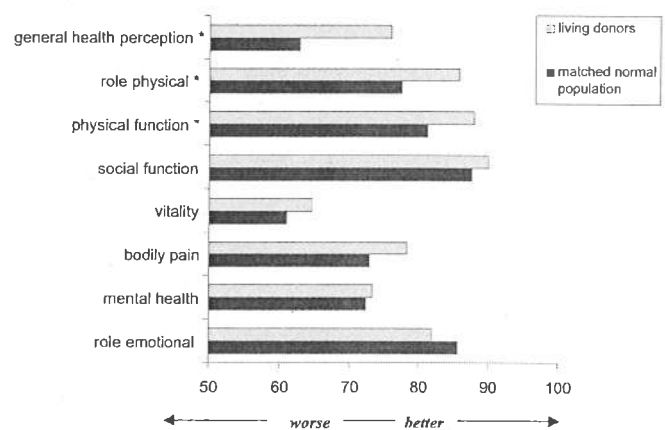


FIGURE 1. Short Form (SF)-36 quality of life (QOL) score of renal donors compared with age-, gender-, and residence-matched (East or West Germany) healthy population (paired *t* test). *, significant difference.

SF-36 item	overall (n=105)	male (n=34)	female (n=71)	21-30 (n=2)	31-40 (n=12)	41-50 (n=26)	51-60 (n=40)	61 and older (n=25)
phys. function	+		+				+	+
phys. role	+		+			+	+	+
bodily pain			+		-			
gen. health	+	+	+			+	+	+
vitality					-		+	
soc. function								+
emotional role								
mental health								

FIGURE 2. SF-36 questionnaire: Significance level of differences between scores for donors and references for the complete study group, as well as referring to gender and age group. +, donors' scores significantly better than references; -, donors' scores significantly worse than references; n, number of donors in each study group.

Female donors scored better in seven of eight items, with significant differences for "physical function," physical role," "bodily pain," and general health" (Fig. 2).

Statistical analysis revealed no influence of kinship with the recipient on donor scores. Also, time of follow-up (time passed since donation) or the applied surgical technique (laparoscopic vs. open) did not differ between the donors scoring better or worse than references.

Giessen Subjective Complaints List-24 Questionnaire

A total of 104 donors completed the GBB-24 questionnaire (Fig. 3). The well-being of 56.8% to 76% of the donors was equal to or better than that of the average population, adding up to 73.1% of the donors "feeling better" than the reference. In contrast with the SF-36 questionnaire, those aged 31 to 40 years had less psychosomatic reasons for physical complaints than the donors of the other age groups, which was even significant for the items "cardiac complaints" and "gastric complaints." There were likewise no differences when donors were grouped according to gender or relatedness; 6.7% to 17.3% of the donors scored worse than the

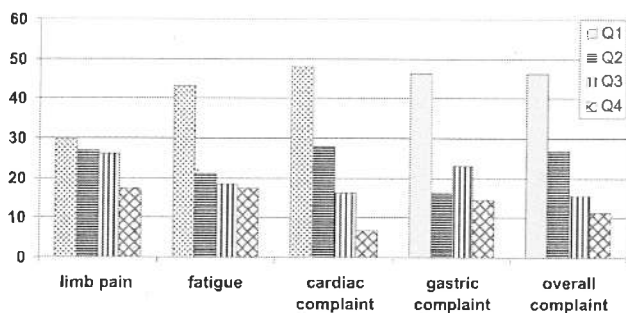


FIGURE 3. Giessen Subjective Complaints List [Giessener Beschwerdebogen] (GBB)-24 questionnaire. Physical perception after organ donation with complaints according to the five items. Proportion of donors feeling better (Q1), equal (Q2 and Q3), or worse (Q4) than the average population.

normal population (Q4), with "fatigue tendency" and "limb pain" as the dominant complaints. Again, donor complications were associated with significantly worse scores for all items compared with donors without complications. When recipient complications occurred, all scores were worse than for donors whose recipients experienced no complications, with significant differences for "limb pain," "fatigue tendency," and "overall subjective complaints."

Additional Questions

The additional questionnaire was answered by all responding donors. Donors' sources of information about LDKT were primarily the recipients themselves (48%). One third of the donors obtained information from the media, and only one donor obtained information from the internet; 17% were informed by friends and family, and only another 17% received information from their doctors.

When asked about the influence of organ donation on their physical situation, 81.1% of the donors stated that they did not experience complaints related to organ donation; 82.1% of the donors reported an equal or better health status than before donation; 91.5% of the donors reported no change in their leisure time activities; 95.3% did not experience a change in their household work; 18.9% of the donors experienced short- or long-term health impairment including poor wound healing, hernia, and pain, but only four experienced permanent impairment (pain); and 89.6% of the donors were currently not taking analgesics. Of the 11 patients who reported analgesic intake, only 5 attributed pain to organ donation (one with incisional hernia, four with lower back pain). Medical follow-up was performed by the outpatient department of a renal transplantation center in 33% of cases, by a general practitioner in 30%, by a nephrologist in 26%, and by a urologist in 11%; 95% of the donors underwent a medical check-up at least once per year.

The relationship between donor and recipient remained unchanged in 80% and improved in 20% of cases; 34.9% of the donors reported anxieties concerning the future, with one third each referring to their own health, their work and health insurance, and the recipients' health; 44% thought that psychologic follow-up was sufficient, and 33% did not.

Six donors reported work-related disadvantages in relation to their social life. We elucidated the reasons in additional telephone interviews. Three donors were unemployed. One donor had worked as a truck driver for several years after organ donation, but because he developed arterial hypertension and other illnesses (osteoporosis), he was not able to work more than 15 hr per week; he applied for retirement pay because of disablement. The second, who demonstrated postoperative hernia, lost her job during the reunification process in Germany. The third reported conflicts with her employer because she often had to take her child, to whom she had donated the kidney, to a doctor or a hospital. At the time of the telephone interview she had just started her own business. One donor had lost her business: Because of postoperative complications (hernia) she was not able to lift heavy loads without pain and therefore gave up her clothing shop. Two donors could no longer work at the same job as before. One had worked as a gardener for 1 year after organ donation and developed pyelonephritis in the remaining kidney. His doctor recommended not working outdoors anymore. The other

was working in a kitchen but could not lift heavy loads anymore after organ donation. Altogether, complications resulting from kidney donation had a negative impact on donors' work in three of the six cases reporting work-related disadvantages.

Financial disadvantages as the result of organ donation were reported by 14 donors. This included additional costs for the operation and follow-up, loss of insurance premium or retirement pay, and unemployment.

When asked about their (multiple) reasons for donating a kidney, 103 donors wished a life free from dialysis for the recipient, and 98 wanted to spare the recipient a long waiting period for a cadaveric organ or further complications related to dialysis. Seventy donors longed for an improvement in their family situation after kidney transplantation; 93.4% of the donors would agree to donate again if it were possible. This was not influenced by postoperative donor complications or recipient outcome; 92.4% of the donors would recommend living kidney donation.

DISCUSSION

The response rate of 89.8% is the second highest achieved in assessing the QOL of living renal donors with the SF-36 (3, 12, 15, 16). Donors in our study generally replied quickly, some of them stating that they were happy that they had not been "forgotten." Answers came from as far away as the United States, Turkey, and Hungary.

One of the strengths of our study is that we compared pairs of subjects and controls matched for gender and age, thus adjusting the control population to the population of interest. Only Fehrmann-Ekholm et al. (12) reported a matched-pair study, whereas other studies using the SF-36 compared their findings with the scores of the general population (3, 15). The present study is also the first to apply the GBB-24, a German questionnaire, to this specific group. Nevertheless, comparison of our findings is difficult because of the lack of standardization, the small number of studies performed with the same questionnaire, and the regional character of our study (4, 5, 17, 24, 25).

Donors mostly reported a better QOL than references, independent of gender, kinship, and age. This finding has been described by others and supports the practice of LDKT (3, 12, 13–16). It may in part be attributable to the fact that before kidney donation donors have a significantly higher QOL compared with references, thus possibly a "reserve" for the time after LDKT, as Smith et al. (16) found in a longitudinal study. Donors' QOL in their study decreased significantly after the operation, but was still better than references' QOL because donors started with a higher score. Donors' QOL strongly depends on the QOL of the recipients after kidney transplantation, which is reflected by the close association of donor's QOL and recipient's outcome. In our study the risk of negative effects on the donor was up to 10 times higher in cases in which the recipient demonstrated graft loss or died. Other studies reported that in a situation with graft failure or recipient death, more than 11% developed suicidal thoughts and 15% of the donors were found to develop depression (25). Although situational depression in these circumstances can be expected, more than 80% would like to be offered mental health referrals in a situation in which severe

recipient complications occur (25). Also, Schover et al. (4) and Westlie et al. (5) found that donors whose grafts were unsuccessfully transplanted had a worse QOL than "successful" donors. Nevertheless, some authors found no association of graft function and donors' QOL, and the results of the different studies remain controversial (15, 24).

Donor complication rate was high in our study and had a significant impact on donors' QOL. Kasiske et al. (26), who summarized several single-center studies on LDKT, reported a mean overall complication rate of 32% and a major complication rate of 4.4%. Hernias after donor nephrectomy were found in less than 1% (10% in our study), and wound infections were found in approximately 5% (11% in our study) (26–28). A reason for the high rate of postoperative complications in our study may be the surgical access site: Two thirds of our complications occurred after subcostal or median open access. To avoid hernias for open transperitoneal access, a transverse incision (27) or a retroperitoneal access with a flank incision (29) is recommended. Complications in laparoscopic kidney retrieval have approximately the same share and kind of complications as the open operation (28). Since the start of laparoscopic organ procurement in our department in 1999, the number of complications has decreased significantly. Altogether, avoiding surgical complications improves donor's long-term QOL. All efforts must therefore be taken to minimize postoperative donor complications.

For donors aged 31 to 40 years at the time of the study, kidney donation had an overall negative impact on QOL. Statistical analysis revealed no impact of the differences in demographic data. Because scores of the GBB-24 did not differ either, a greater psychosomatic impairment in this age group can also be excluded. Therefore, age in itself seems to be the only risk factor for this group. Additional telephone interviews revealed no specific negative situations in donors of this age group. Fehrmann-Ekholm et al. (12) and Jacobs et al. (30) also reported a decline in the QOL of younger donors. They concluded that young donors probably do not "have time to be in the hospital" because of family and career reasons. Causes for the findings in our study can only be speculated. Donors may have had a smaller "reserve" of a good QOL. They comprised a small subgroup mostly from the eastern part of the country where economy is not stable and pressure from work may influence the donor. A longitudinal study would be necessary to support this speculation. Conclusions must be made cautiously and can only be tentative because this age group comprised only 12 donors, differences were significant for only two items, and approximately half of all donor complications and 56% of all negative recipient outcomes occurred in donors aged 40 years or younger. Nevertheless, we disagree with Fehrmann-Ekholm et al. (12), who concluded that older donors should be preferred for living kidney donation. Also, Isotani et al. (15) reported that donors aged less than 50 years scored better than older donors. We believe that in times of increasing organ shortage, younger donors should not be neglected. Their special demands should be further elucidated.

More than one third of the donors in our study reported anxieties concerning the future and thought that psychologic follow-up was not sufficient. Depression and anxiety, even suicidal tendencies and suicides, of donors have been reported before. This may be because of the pressure for

donation experienced by the donor. Kärrfelt et al. (14) reported that a majority of kidney donors were under high emotional strain and experienced psychosomatic or psychiatric symptoms. Also, loss of attention for the donor once the kidney had been donated was reported as negatively affecting donors QOL, as well as donors who thought that they were insufficiently informed about the impact and consequences of living kidney donation on their well-being (4, 12, 14, 25). We believe that preoperative information of the donor must be intensified. The donor must be aware of potential psychologic and physical sequels of organ donation. Also, in addition to medical follow-up, lifelong psychologic counseling should be offered.

Answers to the open questionnaire showed that donors mostly received information on LDKT from the recipient and the media. The decision to donate a kidney was predominantly altruistic, but more than two thirds of the donors also hoped for an improvement of their whole family situation. The relationship between donor and recipient did not deteriorate in any case and even improved for one fifth. These findings are in accordance with others (11, 12, 14). We believe that the field of public information on the possibility of LDKT still should be improved.

Stress for the donors in our study was because of an experienced or anticipated negative impact of kidney donation on job, finances, or health; 13% experienced a negative impact on their financial situation, and this in turn affected their QOL. Few donors reported pain because of organ donation, and 3% to 5% of all living kidney donors were found to have not fully recovered after kidney donation. This proportion is in accordance with the results of others (3, 6, 15). Also, three donors in our study lost their job because of complications of kidney donation, and one third reported fear of the future. An impact on finances and work has been reported by other studies, as well as stress and dissatisfaction in donors who thought they were inadequately informed before surgery (3, 4, 15). Notably, although some studies found donors more ambivalent toward organ donation after having experienced a complication (3, 4, 30), donor or recipient complications in our study did not affect the willingness to make the same decision again. Also, the relationship between donor and recipient in our study remained stable or even improved after organ donation. Shover et al. (4), Westlie et al. (5), and Kärrfelt et al. (14) also found an increased companionship between donor and recipient.

Most donors would be willing to donate again or encourage others to consider kidney donation. Several other studies revealed similar proportions of positive attitudes toward donation (3-5, 12, 16, 26). Donors' motivation for medical follow-up in our study group was higher compared with others (12, 31). This may be partly because German legislation demands a lifelong follow-up of organ donors.

In summary, our findings show that an impact on younger donors' QOL should not be underestimated in living-kidney donation. Preoperative information should be intensified to prepare the donor for potential psychologic and physical sequels of organ donation. Also, all effort must be taken to minimize the rate of postoperative complications, because donor and recipient complications both directly affect donors' QOL. In addition to medical follow-up, lifelong psychologic counseling should be offered to help cope with

the impact of organ donation on donors' QOL, especially for younger donors. Also, any financial disadvantages associated with organ donation must be prevented to reduce fears associated with LDKT. Nevertheless, results of the study support the practice of living-kidney donation. We believe that LDKT should be further encouraged.

There are several limitations to this study. This is a retrospective study covering a long study period, and response rates depended on the time elapsed since LDKT. Also, the rate of donor complications was high compared with other studies. Finally, a local character of the findings and a center effect cannot be excluded. To overcome speculations, prospective, longitudinal studies, such as the one performed by Smith et al. (16), may help to further elucidate donors' QOL in the future.

ACKNOWLEDGMENTS

Special thanks to Gerda Siebert, Institute of Biometrics of the Humboldt University, Berlin, for her support in calculating the statistics. Further thanks to the staff of the Institute of Psychology, University of Hamburg (whose Director, Professor Bullinger, translated, introduced and validated the SF-36 in Germany), for valuable discussions concerning the optimal evaluation of the data.

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Appendix

Open questionnaire on kidney-donation-related issues

1. How did you learn about the possibility of living kidney donation?

- media (newspaper, television, radio)
 friends/acquaintances
 intended kidney recipient
 other:

Physical effects of kidney donation

2. Has the kidney donation led to direct complaints?

- Yes permanent pain
 disturbed wound healing
 rupture of scars/hernia
 other
 No

3. Are you currently taking pain medication?

- Yes Why?
 No

4. Has the donation led to any new illness?

- Yes high blood pressure (hypertension)
 increase of protein in urine (proteinuria)
 worsening of kidney function
 other
 No

Effect of kidney donation on social life and work

5. Do you or did you have disadvantages in your work after kidney donation?

- Yes Which?
 No

6. Have your leisure activities changed?

- Yes How?
 No

7. Have your household activities changed?

- Yes How?
 No

Follow-up and financial situation

8. Have you been in outpatient after-care following your kidney donation?

- Yes family doctor
 nephrologist
 urologist
 transplant center
 other
 No

9. At what intervals do you have after-care check-ups?

- 3 months 6 months 1 year other

10. Do you or did you have any financial disadvantages because of the donation?

- Yes Which?
 No

11. Do you or did you have any problems with your health insurer regarding reimbursement of the costs of donation or medical follow-up?

- Yes Which?
 No

12. How would you describe your current health compared with the time before the donation?

- worse better unchanged

Appendix (Continued)

Open questionnaire on kidney-donation-related issues

13. Are you anxious about your own future?
- Yes
 - No
 - Don't know
 - worsening of my own health
 - worsening of the function of the donated kidney
 - work-related concerns
 - health insurance coverage
 - other
14. Do you feel that you have so far been adequately taken care of?
- Medically Yes No Don't know
- Psychologically Yes No Don't know
- Psychologic part*
15. What was your motivation for donating a kidney? (multiple answers possible)
- life off dialysis for the recipient
 - complications of dialysis
 - relieving the family situation
 - spare the recipient long waiting time
 - other reasons:
16. Would you make the decision to donate a kidney again?
- Yes
 - No
 - Don't know
17. Would you encourage others to donate a kidney?
- Yes
 - No
- Why?
18. Has your relationship with the recipient changed?
- better
 - worse
 - unchanged
19. If you could donate a kidney again, would the surgical technique of kidney removal be important (open surgery or laparoscopy = "keyhole surgery")?
- No
 - Yes
 - Don't know
- Which technique would you prefer?
- "keyhole surgery"
 - open incision of the abdomen
20. Is there anything else you consider important?
-

Thank you for your time and cooperation

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