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. Buddé,5 L. Fritsche,5 Stanislaw Morgera,2 H. H. Neumayer,1 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.

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Living-donor kidney transplantation (LDKT) has been encouraged and increasingly performed because of its excellent results and the persistent lack of cadaveric kidney donors. 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 (1.11.); before this, the evaluation was performed by a
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 [Giesener 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 [Giesener 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 (1,611 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 = 75%–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 (E.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>
<thead>
<tr>
<th>TABLE 1. Description of the Short Form-36 health status scales and interpretation of high and low scores</th>
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</thead>
<tbody>
<tr>
<td><strong>Low score</strong></td>
</tr>
<tr>
<td><strong>General health perception</strong></td>
</tr>
<tr>
<td><strong>Social function</strong></td>
</tr>
<tr>
<td><strong>Vitality</strong></td>
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<tr>
<td><strong>Bodily pain</strong></td>
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<td><strong>Physical role</strong></td>
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<td><strong>Physical function</strong></td>
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<td><strong>Mental health</strong></td>
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<tr>
<td><strong>Emotional role</strong></td>
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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. Categoric 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 58 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 (1). 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 subject 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 function,” 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.”

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

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

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**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.
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 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 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 (osteoarthritis), 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 any-
more after organ donation. Altogether, complications result-
ing 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 donat-
ing 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 complica-
tions or recipient outcome; 92.4% of the donors would rec-
ommend 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 popu-
lation (3, 15). The present study is also the first to apply the
GGB-24, a German questionnaire, to this specific group. Nev-
ertheless, comparison of our findings is difficult because of
the lack of standardization, the small number of studies per-
formed with the same questionnaire, and the regional char-
acter 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 longitudi-
dinal study. Donors’ QOL in their study decreased signific-
antly 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 associ-
ation 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 de-
pression (25). Although situational depression in these cir-
cumstances 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 "success-
ful" 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 compi-
lcation rate of 4.4%. Hernias after donor nephrectomy were
found in less than 1% (10% in our study), and wound infec-
tions were found in approximately 5% (11% in our study)
(26–28). A reason for the high rate of postoperative compli-
cations 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
flapless incision (29) is recommended. Complications in lapa-
roscopic kidney retrieval have approximately the same rate
and kind of complications as the open operation (28). Since
the start of laparoscopic organ procurement in our depart-
ment in 1999, the number of complications has decreased
significantly. Altogether, avoiding surgical complications im-
proves 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. Sta-
nistical analysis revealed no impact of the differences in de-
mographic data. Because scores of the GGB-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 inter-
views 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 out-
comes occurred in donors aged 40 years or younger. Nev-
ertheless, 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 re-
ported anxieties concerning the future and thought that psy-
chologic follow-up was not sufficient. Depression and anxi-
ety, even suicidal tendencies and suicides, of donors have
been reported before. This may be because of the pressure for
donation experienced by the donor. Kärrefelt 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 psychological and physical sequelae 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 Kärrefelt et al. (14) also found an increased companionship between donor and recipient.

Most donors would be willing to donate again and 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 sequelae 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.

REFERENCES

### 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
   □ complications of dialysis
   □ for the recipient
   □ relieving the
   □ spare the recipient long waiting time
   □ family situation
   □ 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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