# Red Flags in the Living Kidney Donor Process

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## ABSTRACT

**Background.** Ideally, no live kidney donor should regret their decision or feel they were not fully prepared for the process. Unfortunately, this is not a reality for all donors. The aim of our study is to identify areas for improvement, focusing on factors (red flags) that predict less favorable outcomes from a donor perspective.

**Materials and Methods.** A total of 171 living kidney donors responded to a questionnaire with 24 multiple-choice questions and space for comments. Less favorable outcomes were defined as lower satisfaction, extended physical recovery period, long-term fatigue, and longer sick leave.

**Results.** Ten red flags were identified. Of these factors, more fatigue (range, $P$ = .000-0.040) or pain (range, $P$ = .005-0.008) than expected while still in hospital, the actual experience being harder or different than expected (range, $P$ = .001-0.010), and the donor wishing to have had but not having been offered a previous donor as mentor (range, $P$ = .008-.040) correlated significantly with at least 3 of the 4 less favorable outcomes. Another significant red flag was keeping existential issues to oneself ($P$ = .006).

**Conclusion.** We identified several factors indicating that a donor could be at an increased risk for a less favorable outcome after donation. Four of these factors have, to our knowledge, not been described earlier: more early fatigue than expected, more postoperative pain than anticipated, not having been offered a mentor at an early stage, and keeping existential issues to oneself. Attention to these red flags already during the donation process could help health care professionals to act early to avoid unfavorable outcomes.

LIVING donor kidney transplantation is a great advantage for the recipient, resulting in better renal function and superior long-term graft and patient survival compared with deceased donor kidney transplantation [1]. However, the use of live donors entails a special responsibility to these individuals. The ultimate goal is for every donor to be satisfied with their decision afterwards and feel that they were fully prepared for the evaluation phase, the donation, and the postoperative course.

Transplant centers have standardized routines that meet the basic requirements for evaluating a live donor. Because different donors can have different needs, the donation process may need to be individualized. Personalized medicine entails working to improve treatment outcomes by adapting the process to the individual patient́s needs in real time [1,2]. It is therefore important to evaluate the quality of the donation process. In this study, the experiences of 171 live kidney donors were evaluated using a questionnaire, covering a period starting with the decision phase and ending 1 year postoperatively. In addition to finding areas for improvement, we also aimed to identify factors (red flags) able to predict, already during the process, an increased risk for

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an unsatisfactory outcome from a donor perspective. If such early factors could be identified, health care could potentially intervene to increase living kidney donors' satisfaction.

## MATERIALS AND METHODS

During the 7-year study period, 229 living donor kidney transplantations were performed at Karolinska University Hospital in Stockholm. Twenty-one of these transplants were excluded due to language barriers (n = 12) or donors who lived abroad or whose addresses were unknown (n = 9). The remaining 208 donors received the questionnaire. The characteristics of the respondents are shown in Table 1.

The questionnaire was sent out with written information about the study, with 2 subsequent reminders sent to those who did not respond. A total of 171 donors (82%) responded and were included in the final analysis. The respondents' answers were pseudonymized so that the investigators could not link a specific response to a specific participant.

The questionnaire contained a total of 39 questions based on the experience of Swedish living kidney donors (LKDs) obtained from meetings and based on previously published studies of living kidney donation, and was reviewed by coordinators who work with donors and recipients, transplant surgeons, and a senior psychologist, all with many years of experience of living donor kidney transplantation. Most of the questions offered a choice of preset responses with space allotted for additional comments. The relevance and clarity of the questions and response alternatives were also tested in a pilot study on previous LKDs (n = 7) and minor adjustments made before the final version of the questionnaire was sent out. This article reports on the findings of 24 questions (listed in Table 2) relevant to the aim of the current study. The questionnaire reflects donor experience at least 1 year after donation.

**Table 1. Respondent Characteristics**

| Sample size | 208 |
|---|---|
| Response rate | 82%/(n = 171) |
| Sex, male/female | 41.5%/58.5% |
| Age at donation | % |
| - 20-30 y | 3.5 |
| - 31-40 y | 15.9 |
| - 41-50 y | 29.4 |
| - 51-60 y | 33.5 |
| - 61-70 y | 17.1 |
| - >70 y | 0.6 |
| Relation to recipient | % |
| - Partner | 25.7 |
| - Parent | 39.8 |
| - Sibling | 13.5 |
| - Other relative | 10.5 |
| - Friend | 5.3 |
| - Colleague | 1.2 |
| - Anonymous | 2.3 |
| - Other | 1.8 |
| Years since donation | Number |
| - 1 | 26 |
| - 2 | 28 |
| - 3 | 19 |
| - 4 | 28 |
| - 5 | 19 |
| - 6 | 30 |
| - 7 | 21 |
| Recipient's graft function at time of questionnaire | % |
| - It functions well | 83.0 |
| - It functions but has deteriorated | 7.0 |
| - Back to dialysis | 5.3 |
| - Recipient deceased | 2.9 |
| - Do not know | 1.8 |

Four of the questions used concerned the donor's views on information received during the different phases of the donation process: the decision to donate, the donation evaluation, the operation, and after the operation. When analyzing how information or lack of information influenced outcome, we summarized responses from the 4 phases into 2 groups—one group that felt well informed throughout, and another group who felt they lacked information in one or more of the phases and were thereby insufficiently informed.

For the first year of the period covered by the study, the mode of surgery was transperitoneal laparoscopy. For the rest of the study period, the donors underwent hand-assisted retroperitoneal laparoscopic nephrectomies. Overall, the most common complications were perioperative injury to vessels of the donor kidney (1.7%) and postoperative urinary leakage (4.5%) [3]. The postoperative stay in the hospital was usually 5 days.

The analysis was conducted on assessable answers only and thus we have excluded all 6 do not know/do not remember responses from the results. Based on previous studies [4,5] showing age-related donor differences participants were divided into 3 age groups: younger (20-40 years), middle-aged (41-60 years), and older (≥61 years) donors.

Our hypothesis was that certain background factors and events during the donation process could indicate that the LKD was at increased risk of having a more negative experience of their donation. The outcome parameters were defined as one of 4 unsatisfactory outcomes: the presence of long-term fatigue, prolonged duration of sick leave, extended time to physical recovery, and lower overall satisfaction with the donation.

The study was approved by the Regional Ethics Committee (Registration no. 2011/1190-31/5). This study contains no organs/tissues procured from prisoners.

### Analysis

Results from categorical variables are presented as frequencies and percentages, and results from continuous variables as mean and SD or median and IQR (25th-75th). The $\chi^2$ test or Fisher's exact test were used to analyze the association between the categorical responses and sex and age groups. Spearman's rank correlation was used to correlate certain background factors with the outcome variables and Mann-Whitney *U* test and Kruskal-Wallis test were used to compare different subgroups with respect to the outcome variables. To analyze whether age and/or sex affect the relationship between the risk factors and either sick leave or physical recovery, a 3-way analysis of variance was used. Before these analyses, the outcome variables were log-transformed due to positive skew. Answers to the long-term fatigue que*stion* (yes/no) were analyzed using multiple logistic regression. Due to an insufficient number of individuals, only the 2-factor interactions were included in the models. Satisfaction is negatively skewed and, given the nature of the scale (visual analogue scale), the data level is ordinal. The Mann-Whitney *U* test and Spearman rank correlation were therefore used to study the relationship between overall satisfaction and the risk factors for men and women separately, as well as for each age group. A *P* value of $< .05$ was considered statistically significant.

Statistical calculations were performed using Statistics for Windows 13.5 (TIBCO Software, Inc, Palo Alto, Calif, United States) and SPSS version 27 (IBM SPSS, Inc, Armonk, New York, United States).

**Table 2. Questions and Results (Percent)**

| | | | |
|---|---|---|---|
| **Who asked you to donate?** | | | |
| Nobody, offered myself | 78 | Recipient's family: Who? . . .. . .. . .. | 5 |
| Health care professional | 10 | Other: Who? . . .. . .. . .. | 1 |
| Recipient | 6 | | |
| **To what extent was your decision influenced by the recipient's inconveniences due to kidney failure?*** | | | |
| Very much | 61 | A little | 6 |
| Much | 15 | Not at all | 8 |
| Partially | 8 | Did not perceive that the recipient was inconvenienced | 2 |
| **Was the decision to donate difficult to make?** | | | |
| Very easy | 66 | Difficult | 4 |
| Easy | 25 | Very difficult | 3 |
| | | Other: Please specify . . .. . .. . .. | 2 |
| **Did you experience pronounced or tacit pressure to donate a kidney from those around you, such as family or other potential donors?** | | | |
| Yes | | 9 | |
| No | | 91 | |
| **Did you feel that it was your duty to donate?** | | | |
| Yes | | 12 | |
| Partially | | 22 | |
| No | | 66 | |
| **Should health care staff take a more active role with potential donors in the recruitment phase when the issue of donation is raised?** | | | |
| Yes | | 85 | |
| Neutral | | 9 | |
| No | | 6 | |
| **Did you feel sufficiently informed about donation before you decided to donate a kidney?** | | | |
| Yes, very well informed | 46 | No, lacked some information | 7 |
| Yes, sufficiently informed | 39 | No, lacked a lot of information | 8 |
| **Did you feel that health care provided sufficient support and the information you needed during the evaluation?** | | | |
| Yes | | 82 | |
| No | | 13 | |
| Do not know | | 5 | |
| **Did you have any psychosocial concerns?** | | | |
| Yes | | 71 | |
| No | | 28 | |
| Do not know | | **1** | |
| **How did you deal with the psychosocial concerns that arose in connection with your donation evaluation? (Choose as many answers as apply)** | | | |
| Kept them to myself | 17 | Talked to my recipient | 23 |
| Took them up with health care | 21 | Talked to a priest, imam, or faith leader | 2 |
| Talked to a friend(s) | 18 | Other: Who? _____ | 4 |
| Talked to the family | 35 | Question not relevant for me | 29 |
| Talked to previous living kidney donor | 8 | | |
| **How did you experience the final notification that you were accepted as a donor? (Choose as many answers as apply)** | | | |
| I felt proud to qualify as a donor | 39 | I had mixed feelings of being happy to be healthy but worried about the operation | 13 |

(*continued on next page*)

| | | | |
|---|---|---|---|
| I was happy and proud to be healthy and have a healthy body | 52 | I had mixed feelings of being happy to be healthy but worried about my future health | 7 |
| I felt I could do a good deed | 41 | I had hoped to not be approved to avoid donating | 0 |
| I felt happy that I could share a healthy kidney | 64 | I felt neither happy nor sad (neutral) | 0.6 |
| I was happy to be able to give health to the recipient | 79 | Other: Please specify . . .. . .. . .. | 2 |

**Had the information you received from health care prepared you for what was involved with undergoing an operation?**

| | | | |
|---|---|---|---|
| Yes, very well | 51 | No, too little | 5 |
| Yes, sufficiently well | 29 | No not at all | 1 |
| Yes, partially | 11 | Do not know | 1 |
| | | Not needed | 2 |

**The time right after the surgery, when you were in the hospital, how much fatigue or pain did you experience?**

| **Fatigue** | | **Pain** | |
|---|---|---|---|
| More than expected | 30 | More than expected | 19 |
| As expected | 44 | As expected | 40 |
| Less than expected | 26 | Less than expected | 41 |

**Did you feel that health care provided sufficient support and the information you needed after the operation?**

| | |
|---|---|
| Yes | 77 |
| No | 15 |
| Do not know | 8 |

**How long were you on sick leave after the operation? _____weeks**

Mean 8 ± 5.2 wk, median 7 wk (25th-75th percentile 4-11 wk; full range, 0-30 wk)

**What reactions did you encounter at your workplace due to having volunteered to be a donor? (Choose as many answers as apply)**

| | | | |
|---|---|---|---|
| Positive that I stood up for a fellow human being | 76 | No reaction at all | 2 |
| Negative that I was away from work due to examinations and surgery | 6 | Never told anyone at my workplace | 0 |
| Curiosity from my co-workers, why I did it and what it included | 47 | Do not work | 11 |
| | | Other: Please specify . . .. . .. . .. | 7 |

**How long time did it take after the operation before you were back to the same physical fitness as before the operation? _____ months**

Mean 5.4 ± 4.6 mo, median 4 mo (25th-75th percentile 2-6 mo; full range, 0.75-36 mo)

**The county council has undertaken to reimburse the part of one's earned income not covered by social insurance and other expenses related to the donation.**
**Did you take the compensation from the county council for lost earnings and other expenses you had in connection with the donation?**

| | | | |
|---|---|---|---|
| Yes, I took the compensation I was entitled to | 85 | No, compensation was not offered | 6 |
| No, compensation was offered but I didn't bother to take it | 9 | | |

**Did discomfort/problems arise during the first year after the operation in ways that you did not expect and that disrupted your bodily function, ability to work, or your family or social life? (Choose as many answers as apply)**

| | | | |
|---|---|---|---|
| Yes, discomfort around the surgical scar | 23 | Yes, small problems were difficult to deal with | 2 |
| Yes, ugly scars | 17 | Yes, frustration due to lack of medical follow-up | 3 |
| Yes, discomfort where the kidney had been | 7 | Yes: Please specify _____ | 12 |
| Yes, pain related to the operation | 10 | No, I feel better than before the operation | 4 |
| Yes, lack of energy, fatigue, or exhaustion | 19 | No, nothing at all | 46 |

(*continued on next page*)

| | | | |
|---|---|---|---|
| Yes, depressed or slightly depressed | 6 | I do not remember | 3 |
| Yes, a feeling of having lost something | 2 | | |
| **How well did the image you had prior to the donation match your actual experience of donating a kidney?** | | | |
| It was easier than I expected | 34 | It turned out differently than I imagined | 12 |
| Agreed well with what I imagined | 38 | I do not remember | 4 |
| It was harder than I imagined | 12 | | |
| **Did health care staff offer you the opportunity to talk to a previous living kidney donor in connection with your donation process?** | | | |
| Yes, talked to a previous donor and it was useful | 9 | No, but wanted to | 26 |
| Yes, talked to a previous donor but it did not help much | 2 | No, had no need for it | 49 |
| Yes, but had no need for it | 6 | Do not know | 8 |
| **What recognition from health care/society do you, did you or would you appreciate, for your efforts as a kidney donor?** | | | |
| Annual/biennial check-up at the kidney clinic | 81 | That my experiences as a donor are used to help others undergoing the donation process or to help spread knowledge about living donation | 51 |
| A work of art at Karolinska University Hospital that draws attention to all living donors | 7 | Nothing at all | 5 |
| | | Other: Please specify _____ | 14 |
| **Information throughout the process** | | | |
| I felt well informed | 64 | I felt insufficiently informed | 36 |
| **All in all, I look back with satisfaction on my donation (place an X on the line to indicate your level of satisfaction)** | | | |
| **Not at all**———————**Very much** | | | |
| Mean value 8.9 ± 1.7, median 9.5 (25th-75th percentile 8.4-10; full range, 0.4-10) | | | |

* Anonymous donors not included, as they have no knowledge of the identity of the recipient.

## RESULTS

Table 2 summarizes the results from the questionnaire and Table 3 identifies what we call "red flags," consisting of early predictors for less favorable outcomes that could allow identification of donors in need of closer attention. A more in-depth analysis also demonstrated the following findings.

### Pain and Fatigue Directly After the Operation

While still in the hospital after the operation, 19% of the donors experienced more pain and 41% experienced less pain than they had expected, and 30% experienced more fatigue and 26% experienced less fatigue than expected. These 2 risk factors correlated significantly with 3 (range, $P$ = .005-0.008) and 4 (range, $P$ = .000-.040), respectively, of the less favorable outcome parameters. The odds ratio for long-term fatigue was 5.5 times higher if the donor had experienced early fatigue. Ten of the 32 participants who experienced long-term fatigue also suffered from long-term pain.

### Psychosocial Concerns and Keeping Them to Oneself

Many of the LKDs stated that they had thoughts about the psychosocial aspects of the donation (72%). Some donors had talked about these issues with others, but 17% kept their thoughts to themselves. Donors who kept psychosocial concerns to themselves had an increased risk for long-term fatigue ($P$ = .006), with 39% stating they had experienced long-term fatigue compared with 13% of those who stated they had talked to others about this. More men (25%) kept such issues to themselves than did women (12%) ($P$ = .031). The odds ratio for long-term fatigue was 5.5 times higher for donors who kept psychosocial concerns to themselves.

### Wanting but not Having Been Offered a Mentor

Those who would have liked to have had a mentor had longer sick leave duration ($P$ = .038), longer time back to baseline physical condition ($P$ = .040), and experienced more long-term fatigue ($P$ = .008) compared with those who had been offered or had felt no need for a mentor.

### Alignment Between Donor Expectations and Actual Experience

Regarding whether predonation expectations coincided with actual experience, most LKDs stated that their actual experience agreed well or was easier (76%) than expected. Fewer, but still a significant number of donors, responded that the actual experience was harder or different (24%) than expected. Donors who experienced the donation as harder or different than what they had expected had an increased risk for prolonged sick leave ($P$ = .010). In this regard, a difference was also found here between age groups, where the sick leave for both younger ($P$ = .042) and older ($P$ = .015) donors was longer when their actual experience was worse than expected. This was not the case in the middle-aged group.

A poor correlation between an LKD's expectations and their actual experience of the donation was also significant for long-term fatigue ($P$ = .001), with the odds ratio for long-term fatigue being 4.3 times higher in these cases. Poor alignment between an LKD's expectations and their actual experience of donating ($P$ = .002) was a risk factor for a lengthier recovery time.

Another aspect that influenced how well an LKD's expectations and actual experience corresponded was how well informed the donor felt: those who felt well informed stated that the experience was as expected (47%) or easier (40%). Very few of the well-informed donors considered the experience harder (8%) or different (5%) than expected. A different result was seen among LKDs who felt insufficiently informed, where fewer responded that the actual experience was as expected (26%) or easier (29%), and more found it harder (19%) or different (26%) than expected. Thus, regarding how well one's actual experience coincided with expectations; we found a significant difference between LKDs who felt well informed as opposed to those who did not ($P$ < .001).

### Duty, Pressure, Decision to Donate, and Recipient's Kidney Function

Most LKDs (78%) offered to donate without being asked and found the decision easy to make. Over 65% of the LKDs did not consider it their duty to donate. Of those who did, men

**Table 3. Risk Factors for Less Favorable Outcomes**

| Risk Factor | Outcome Parameter | | | |
|---|---|---|---|---|
| | Sick leave | Physical recovery | Long-term fatigue | Satisfaction |
| More fatigue than expected postoperatively while still in the hospital | 0.000* | 0.000* | 0.000* | 0.044† |
| More pain than expected postoperatively while still in the hospital | | 0.005* | 0.006† | 0.008† |
| Poor correlation between expected and actual experience | 0.010† | 0.002* | 0.001* | |
| Would have liked to have a mentor | 0.038 | 0.040 | 0.008 | |
| Had psychosocial concerns | | | | 0.009* |
| Kept psychosocial concerns to oneself | | | 0.006* | |
| Felt pressure | | | | 0.003* |
| Felt decision to donate difficult | | | | 0.000* |
| Experienced a sense of duty | | | | 0.036† |
| Recipient kidney function decreased | | | | 0.000 |

Only statistically significant correlations are shown in the table.

* Correlation (r) r < 250 = no relationship.

† Correlation (r) r < 250 r <750 = relationship.

considered it a duty to a greater extent than women ($P = .003$). A small number (9%) of our LKD respondents stated having felt pressure to donate. Overall satisfaction with the donation was influenced by feeling a sense of duty, with middle-aged and female respondents who felt a duty to donate reporting lower satisfaction ($P = .017$ and $P = .031$, respectively). The LKDs who felt the decision was hard to make or felt pressured to donate also reported lower satisfaction, as did donors in cases where the recipient's kidney function had deteriorated.

### Problems During the First Year

Regarding discomfort or other problems during the first postoperative year, the most common response was that the LKDs did not experience any problems (46%), followed by discomfort around the surgical scars (23%).

### Recognition

The types of recognition for having donated a kidney that most of our LKD respondents stated they would appreciate were regular medical check-ups (81%) and that their experience be used to spread knowledge about living donation and to prepare potential future LKDs undergoing the process. More women stated that they would appreciate the latter form of recognition than men did (59% and 40%, respectively) ($P = .014$).

## DISCUSSION

Ideally, living donors should not regret their decision to donate a kidney or feel that they were not fully prepared for the process and outcome. This is still not a reality for all LKDs, however. Transplant centers currently have standardized routines that meet the basic requirements for evaluation of a potential live donor. There may be a need to add to this to meet the individual donor's needs.

In our study, we identified several variables that seemed to negatively influence our 4 outcome parameters (ie, long-term fatigue, duration of sick leave, time to physical recovery, and overall satisfaction with the donation). Recognizing and addressing these issues at an early stage could help to improve outcomes.

### Fatigue While Still in the Hospital

Our findings suggest that experiencing more postoperative fatigue than expected while still in hospital is an important red flag, and this was the only factor that correlated with a negative result in all 4 outcome parameters. Supporting this finding, Wilken et al also found a higher level of fatigue at baseline to be a risk factor for long-term fatigue post donation, which in turn negatively impacted satisfaction [6]. Other studies have found that physical discomfort resulting in a longer time to return to daily activities also negatively impacted satisfaction scores [4,7]. Long-lasting fatigue and difficulty concentrating have often been perceived as psychosomatic in nature [8]. However, similar symptoms are also found in patients who undergo abdominal surgery, a condition called postoperative cognitive dysfunction. Postoperative cognitive dysfunction seems to be related to inflammation and activation of the immune system after surgery and has been investigated in, among others, recipients after kidney transplantation, but to date not in living kidney donors [9,10]. The reduction in renal function when one kidney is removed from the live donor may also enhance the inflammatory response [11]. Thus, there may be several reasons for prolonged fatigue. Those who keep existential thoughts to themselves have also been shown to have a greater risk of prolonged fatigue, and, here, the reason may be of a more psychological nature [8].

Pronounced early postoperative fatigue is thus a warning sign that these donors may require more time to recover and a longer sick leave. Preparing donors regarding the large inter-individual variation in recovery times is an important task for health care. We believe that the question of early fatigue should always be raised with donors before discharge from the hospital.

### Pain While Still in the Hospital

Nineteen percent of our respondents reported experiencing more pain than they had expected directly after the operation. In line with this finding, other studies have also found a correlation between pain while still in the hospital and fatigue [12,13]. Ten percent of the donors in our study experienced chronic postsurgical pain (CPSP) up to 1 year after the donation, which is in line with Bruintjes et al [13]. Another study found CPSP in as many as 41% of the donors [12]. The LKDs in both our study and other studies described CPSP as tiring and exhausting and accompanied by a lack of energy and fatigue [12,13]. Predictors of CPSP include severe early postoperative pain and a preoperative history of mood disorder [12,13].

In the early postoperative phase, live donors as well as other surgical patients should receive optimal and efficient pain treatment. This is important to optimize donor experience of the postoperative course, and has also been found to reduce problems with long-term pain [12−14].

### Expectations vs Actual Experience, Correct and Adequate Information, and Contact With Previous Kidney Donors

Similarly to our study, Traino et al and Menjivar et al found a correlation between satisfaction with information provided before donation and alignment of a donor's expectations and their actual experience of donating [15,16]. In addition, Agerskov et al found that good communication between health care and the donor gave rise to predictability, confidence, motivation, and commitment of the donor, which in turn promoted optimal post-donation outcomes [17].

Individuals with personal experience can convey dimensions and perspectives that add to the medical aspects that health care staff provide [18]. By having previous LKDs and kidney patients serve as mentors and information providers during the donation process, we can hopefully give individuals in the process of becoming LKDs a better overall picture. Waterman et al described a web-based project that presents personal stories

from living donors and recipients that can be used to inform interested parties including potential living donors [19].

On the positive side, there is also a will on the part of the LKDs to provide this resource, with 51% of our LKDs expressing a desire for their experiences as a donor to be used to inform others about living donation.

Others have similarly found the decision to donate to be affected by a donor's awareness of the recipient's reduced quality of life and morbidity due to their kidney disease [17,20].

An area for improvement is the facilitation by health care of predonation access to individuals with personal experience of the LKD process. This would help to provide potential donors with a basis on which to form reasonable expectations.

### Psychosocial Concerns and Handling Them Oneself

Several studies have shown that it is not unusual for donors to encounter different dilemmas during the decision-making process [21,22], which is consistent with our findings. It is important that these concerns are ventilated with others. We found it noteworthy that keeping such thoughts to oneself led to a higher risk for long-term fatigue, and that doing so was more common among male donors. These findings suggest that the importance of ensuring that donors have someone to discuss psychosocial concerns with, and that care providers be more attentive to donors who may be less openhearted—based on our data, in particular to men who fall into this category.

### Duty, Pressure, and Experiencing the Decision to Donate as Difficult

In our study, a sense of duty and feeling pressure to donate appear to be separate phenomena.

Von Zur-Mühlen et al found, like us, that more men felt it their duty to donate than did women [23]. The finding that seeing donation as a duty is more common among men may be related to traditional gender roles in society [24]. An interesting observation in our study was also that, whereas women who felt a duty reported lower satisfaction with the donation than those who did not, duty had no bearing on men's satisfaction.

In a study by Brown et al [25], donors stated that the decision to donate is personal and one must feel comfortable with the decision since it is the donor who must live with it, which coincides with our finding. Studies have also found a perceived lack of support (from family members, friends, and one's social network) for the decision to donate to have a negative effect on donors' experience [17,19,25]. To support truly voluntary donation, it is essential that health care staff always address issues such as duty and pressure during the recruitment phase.

### Recipient Kidney Function

One of the main reasons given by LKDs in our study for donating a kidney was their desire to help the recipient and improve the recipient's health, motivations that corroborate the findings of other studies [26,27]. Coinciding also with our findings, Hanson et al reported that LKD satisfaction with the donation depended primarily on the outcome for the recipient [27]. Failing kidney function in the recipient may cause donors to experience feelings of guilt and helplessness of having no kidney left to give [28]. In cases of deteriorating recipient kidney function, health care has a responsibility to also support the donor [29]. However, permission must always be secured from the recipient before discussing any recipient medical data with the donor.

### Limitations

One of the strengths of this study is the high response rate. A fact that should be kept in mind when reading the results, however, is that in some cases several years had passed between the donation and the donor answering the questionnaire. A kidney donation is nevertheless an extraordinary event that one is likely to remember for the rest of one's life. One should also bear in mind that, although the study shows correlations between different risk factors and the outcome parameters, any causality between them remains uncertain. Still, we believe that the red flags identified can help to provide guidance in the identification of donors in need of additional, individualized treatment. As the respondents' answers were pseudonymized, no comparison could be made with medical records.

## CONCLUSIONS

We have identified several factors that, according to this retrospective study, indicate that the LKD is at an increased risk for a less favorable outcome post surgery. Some of these factors that can negatively affect donor satisfaction, including a sense of duty, the pressure to donate, poor alignment between expectations and actual experience, the decision to donate being a difficult one, and unaddressed existential issues, have also been described by others.

We also identified an additional 4 factors (red flags) that, to our knowledge, have not been described earlier. In our study more fatigue than expected while still in the hospital was the strongest predictor of a less favorable donor experience. The first of these—early postoperative fatigue—was found to influence all 4 donor outcome parameters: long-term fatigue, the duration of sick leave, time to physical recovery, and overall satisfaction with the donation. A second, unanticipated postoperative pain was significantly correlated to 3 of the outcome parameters. Such pain and early fatigue should be addressed already during the hospital stay. A third red flag was keeping psychosocial concerns to oneself, where offering a mentor at an early stage in the donation process and identifying donors who do not talk about their existential concerns also seem to be important to improving outcomes. Our data also shows a great variability in time to full recovery, and how alignment of one's expectations and actual experience can affect overall satisfaction with the donation. Health care staff should inform potential donors about the large inter-individual variation in recovery times as a basis for reasonable expectations. Paying attention to these red flags could help health care professionals to individualize treatment and act early rather than trying to handle an already-established problem at a later stage.

## DISCLOSURE

All the authors declare no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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