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ORIGINAL ARTICLE

Psychosocial consequences of living kidney donation: a prospective multicentre study on health-related quality of life, donor–recipient relationships and regret

Lieke Wirken[1,2], Henriët van Middendorp[1,2], Christina W. Hooghof[3], Jan-Stephan F. Sanders[4], Ruth E. Dam[5], Karlijn A.M.I. van der Pant[6], Judith M. Wierdsma[7], Hiske Wellink[8], Elly M. van Duijnhoven[9], Andries J. Hoitsma[3], Luuk B. Hilbrands[3] and Andrea W.M. Evers[1,2,10]

[1]Institute of Psychology, Health, Medical and Neuropsychology Unit, Leiden University, Leiden, The Netherlands, [2]Department of Medical Psychology, Radboud University Medical Center, Nijmegen, The Netherlands, [3]Department of Nephrology, Radboud University Medical Center, Radboud Institute for Health Sciences, Nijmegen, The Netherlands, [4]Division of Nephrology, Department of Internal Medicine, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands, [5]Department of Nephrology, Leiden University Medical Center, Leiden, The Netherlands, [6] Division of Nephrology, Department of Internal Medicine, Renal Transplant Unit, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands, [7]Department of Nephrology, University Medical Centre Utrecht, Utrecht, The Netherlands, [8]Department of Nephrology, VU Medical Center, Amsterdam, The Netherlands, [9]Division of Nephrology, Department of Internal Medicine, Maastricht University Medical Center, Maastricht, The Netherlands and [10]Department of Psychiatry, Leiden University Medical Center, Leiden, The Netherlands

Correspondence and offprint requests to: Lieke Wirken; E-mail: l.wirken@fsw.leidenuniv.nl; Twitter handle: @AndreaEvers

ABSTRACT

Background. Previous studies have indicated decreased health-related quality of life (HRQoL) shortly after kidney donation, returning to baseline in the longer term. However, a subgroup of donors experiences persistent HRQoL problems. To identify which HRQoL aspects are impacted most by the donation and to identify at-risk donors, more specific insight into psychosocial donation consequences is needed.

Methods. The current study examined the HRQoL course, donor-perceived consequences of donation for donors, recipients and donor–recipient relationships, and regret up to 12 months post-donation in donors from seven Dutch transplantation centres. Kidney donor candidates ($n = 588$) completed self-report questionnaires early in the screening procedure, of which 361 (61%) donated their kidney.

Results. Data for 230 donors (64%) with complete assessments before donation and 6 and 12 months post-donation were analysed. Results indicated that donor physical HRQoL was comparable at all time points, except for an increase in fatigue that lasted up to 12 months post-donation. Mental HRQoL decreased at 6 months post-donation, but returned to baseline at 12 months. Donors reported large improvements in recipient's functioning and a smaller influence of the recipient's kidney disease or transplantation on the donor's life over time. A subgroup experienced negative donation consequences with 14% experiencing regret 12 months post-donation. Predictors of regret were more negative health perceptions and worse social functioning 6 months post-donation. The strongest baseline predictors of higher fatigue levels after donation were more pre-donation fatigue, worse general physical functioning and a younger age.

Conclusions. Future research should examine predictors of HRQoL after donation to improve screening and to provide potential interventions in at-risk donors.

Keywords: course, donation consequences, health-related quality of life, living kidney donors, regret

INTRODUCTION

Prospective studies in living kidney donors have shown small decreases in health-related quality of life (HRQoL) shortly after donation, generally returning to baseline in the longer term [1–3]. Also, HRQoL scores after donation mostly return to the level of general population norms [4, 5]. However, uncertainty (e.g. regarding recipient outcome) and distress about the screening or surgery [6, 7] may lead to more serious HRQoL problems in some donors, such as anxiety or fatigue [1, 8, 9]. To identify which HRQoL aspects are impacted most by the donation and to identify at-risk (potential) donors, more specific insight into the psychosocial consequences of donation is needed.

Previous research has mostly used generic HRQoL instruments that do not capture specific relevant donation-related

domains [10, 11]. The donor's perception on donation consequences for themselves, the recipient and their relationship before and after transplantation has mostly been described in retrospective or qualitative studies [12–16]. Furthermore, the presence or absence of regret about the donation decision has mostly been assessed using a single *ad hoc* question which has indicated that a small subgroup of donors experiences regret [13, 17–19]. Previous research assessing decisional regret about healthcare decisions in other patient populations showed that more regret was related to poorer HRQoL. Adverse health outcomes, more ambivalence and lower satisfaction about information provision are potential predictors of regret [20, 21]. Whether such variables also predict regret in kidney donors has not been studied. Risk factors for more post-donation doubts about the donation were lower HRQoL levels, recipient graft loss, medical problems after donation, being an unrelated donor and having a younger age [5].

The current study aims to improve our insight into the potential psychosocial consequences of living kidney donation by prospectively examining the course of generic HRQoL as well as donation-specific domains.

MATERIALS AND METHODS

Procedure

During the data collection period (2011–15), all donor candidates from seven Dutch transplantation centres (Radboud University Medical Center, University Medical Center Utrecht, Leiden University Medical Center, University Medical Center Groningen, Maastricht University Medical Center, Academic Medical Center Amsterdam and VU Medical Center Amsterdam) were invited to participate in the study after their first screening visit. Illiteracy was the only exclusion criterion. After signing informed consent, a questionnaire was sent either by e-mail or on paper. Donors received a similar questionnaire 6 and 12 months after surgery. The Ethics Committee of the Radboud University Medical Center decided that the study did not fall within the scope of the Medical Research Involving Human Subjects Act. Moreover, since the study did not pose any risk for participants, approval by an ethics committee was not required. In all participating centres, the executive board approved the study. The clinical and research activities being reported are consistent with the Principles of the Declaration of Istanbul and the Declaration of Helsinki.

Participants

A total of 588 donor candidates filled out the questionnaire after the first screening visit (75% response rate), of whom 361 donors (61%) donated their kidney. The mean time between screening and donation was 7.0 ± 5.2 months. Reasons for exclusion from the donation procedure are presented in Figure 1. Complete data of 230 donors were available.

Measures

Pre-donation demographic characteristics, intra- and post-operative characteristics. Demographic and intra- and post-operative factors were assessed (e.g. surgery type, hospital stay, complications). Donor complications were derived from the donor's medical files and defined using the Clavien–Dindo classification system [22]. Data on recipient's pre-transplantation treatment and post-transplantation outcome (i.e. graft failure or death) were derived from the Dutch Organ Transplantation Registration system [23].

HRQoL. *Physical functioning* before, and 6 and 12 months post-donation was assessed using the RAND Short Form-36 Health Status Inventory (RAND-SF36; [24]) and Checklist Individual Strength-Fatigue Short Version (CIS; [25]).

The RAND-SF36 is a 36-item questionnaire assessing eight HRQoL dimensions. Physical HRQoL consists of the subscales Physical Functioning, Role Limitations due to Physical Health Problems, Pain and General Health Perceptions, summarized in the Physical Health Composite Score. The Hays norm-based scoring algorithm was applied, transforming raw scores into *T*-scores ($M = 50 \pm 10$ in the general population) [24]. Higher scores represent better HRQoL. Cronbach's α varied between 0.53 (General Health Perceptions) and 0.91 (Role Limitations due to Physical Health Problems).

The CIS short version [25] (four items) assesses fatigue (e.g. 'I feel tired'). Higher scores represent more fatigue. Cronbach's α was 0.80.

Psychological functioning before, and 6 and 12 months post-donation was assessed using the RAND-SF36 mental HRQoL scales Emotional Well being, Role Limitations due to Emotional Problems, Social Functioning and Energy, summarized in the Mental Health Composite Score [24]. Cronbach's α varied between 0.61 (Social Functioning) and 0.83 (Mental Health Composite).

Donor-perceived and recipient-related consequences of donation. *Course of donor and recipient-related functioning.* The impact of (intended) donation on the donor, recipient or donor–recipient relationship was assessed before, and 6 and 12 months post-donation using Visual Analogue Scales (VAS; Supplementary data S1). The domains assessed were donor's perspectives on (i) current recipient's physical and emotional functioning, (ii) recipient limitations caused by the kidney disease or transplantation, (iii) quality of the donor–recipient relationship, (iv) influence of recipient's kidney disease on the donor's daily life, (v) donor responsibility for recipient's well-being and (vi) the extent to which the donor takes care of tasks that the recipient cannot accomplish due to the kidney disease/transplantation. Altruistic donors did not complete these questionnaires. Donors within a kidney exchange programme were asked to think about their known recipient when completing the questionnaires.

Perceived donation consequences. We developed a new questionnaire to specifically assess donor-perceived consequences of donation and transplantation for the donor, recipient and their relationship (Supplementary data S2). Relevant items were based on evaluation of scientific literature and on clinical practice. The questionnaire was first evaluated by a small group of donors to test usability. After revision, Principal Component Exploratory Factor Analysis with Promax rotation and Kaiser

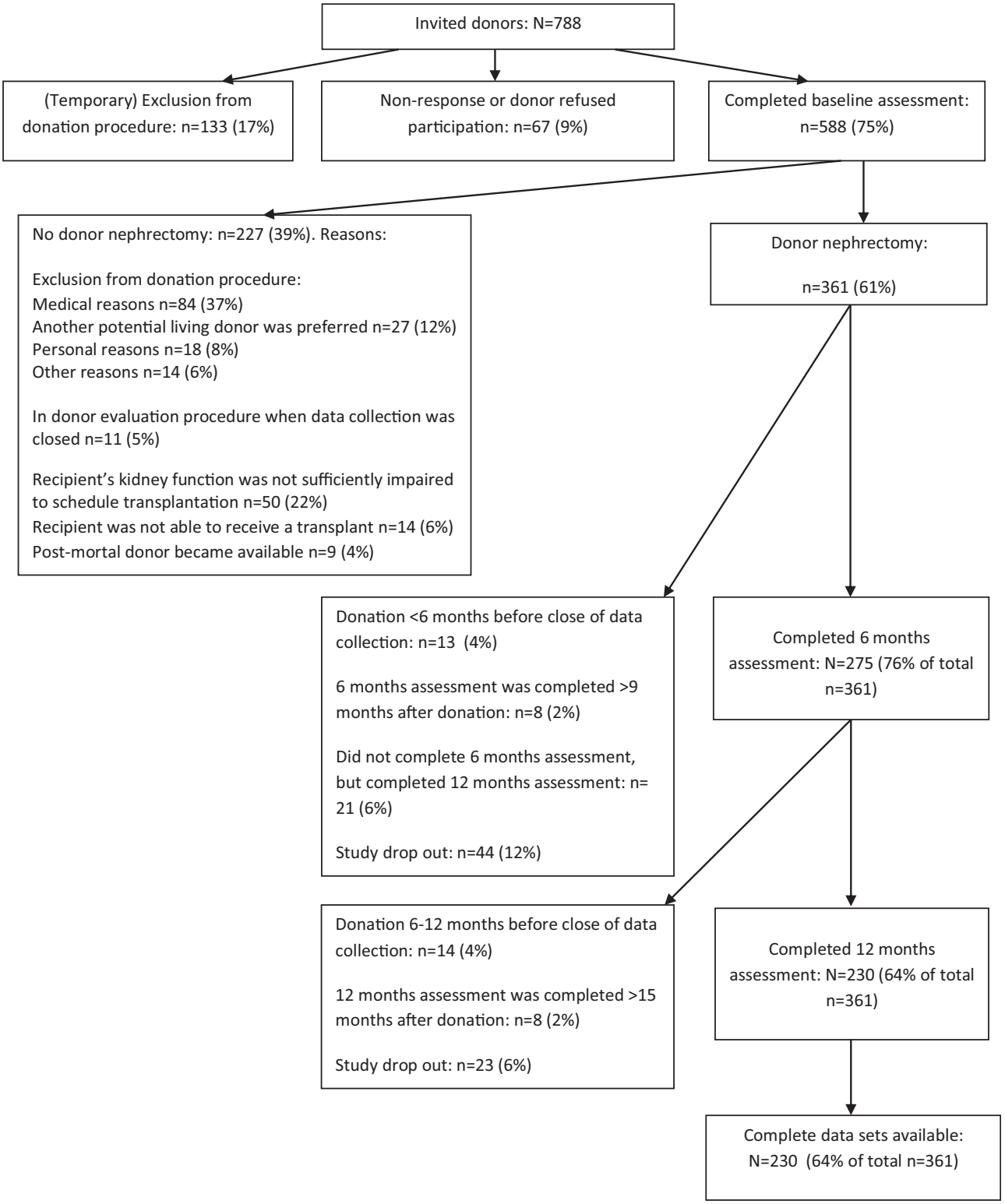

FIGURE 1: Study flow chart.

Normalization was used to identify the scale structure. This Perceived Donation Consequences Scale (PDCS) consisted of 29 items measured on a 5-point Likert scale (1 = strongly disagree, 5 = strongly agree) and showed a consistent four-factor structure in the 6 and 12 months post-donation assessments. The factors assessed donor physical consequences (five items; e.g. 'My recovery from surgery took longer than I expected'), post-donation worries (five items; e.g. 'I am concerned about the performance of my remaining kidney in the future'), recipient consequences (three items; e.g. 'The disease burden of the recipient in daily life has been reduced') and relational consequences (five items; e.g. 'I expected more appreciation and

attention from the recipient'). Higher scores represent a greater impact of donation. Eleven items were excluded because of factor loadings ≤0.40 or cross-loadings ≥0.20, leaving a total number of 18 items. Cronbach's α varied between 0.65 (post-donation worries) and 0.86 (recipient and relational consequences).

Regret about the donation decision was assessed 12 months post-donation using the Decision Regret Scale, measuring distress or remorse about healthcare decisions [21]. In this 5-item questionnaire (e.g. 'It was the right decision'), scores were converted to 0–100 scales. Higher scores indicate a higher degree of regret. Cronbach's α was 0.86. The percentage of donors experiencing decisional regret was expressed by using a cut-off score of ≥30 [20].

Statistical analyses

Normal distribution was verified, transforming skewed or kurtosed variables using logarithmic or reflected transformations in order to enable parametric statistics. Generalized mixed model analyses were conducted to examine the HRQoL course from before to 6 and 12 months post-donation on (i) RAND-SF36 Physical and Mental Health Composite Scores and CIS fatigue and (ii) RAND-SF36 subscales. HRQoL scores were also compared with population norms. Clinically relevant differences between time points were defined as 5-point differences in *T*-scores using the RAND-SF36 [24] and 0.5 SD differences of norm scores using the CIS [25].

Changes in perceived donor's and recipient's functioning and donor–recipient interaction (0–10 Visual Analogue Scale (VAS)) were assessed by means of generalized mixed models. In addition, VAS scores were categorized into four classes: poor (score 0–0.4), fair (0.5–4.4), moderate (4.5–7.4) and good functioning (7.5–10.0) [26]. Similarly, for each factor of the PDCS, mean scores for donation consequences on 5-point Likert scales were categorized into three classes: no–few consequences ($M = 1.0$–1.9), some consequences ($M = 2.0$–3.9) and many consequences ($M = 4.0$–5.0).

The percentage of donors experiencing regret at 12 months post-donation was calculated, and HRQoL differences at the different time points between donors experiencing regret versus those who did not were examined in an exploratory analysis.

Pearson correlation analyses were conducted to examine the association of donor demographic characteristics, pre-, intra- and post-operative donor and recipient health status, and donor measures with regret about the donation decision at 12 months post-donation and fatigue 6 and 12 months after donation. Subsequently, hierarchical multiple regression analyses were conducted for regret 12 months post-donation and fatigue 6 and 12 months after donation, including all variables that showed significant correlations with the outcomes. Analyses were conducted using IBM SPSS Statistics 22.0 [27].

RESULTS

Donor characteristics

Table 1 presents demographic, intra-operative and post-operative characteristics of 230 participating donors. The sexes were almost equally represented (59% female), mean (SD) age was 55.1 (10.7; range 23–76) years, and most participants had secondary-level education (62%). The majority (83%) donated directly to the recipient they knew and underwent laparoscopic surgery (85%). Most donors did not experience complications (83%) and in a minority of recipients, there was graft failure (6%) or death (3%) within the first year after transplantation. Mean (SD) post-donation hospital stay was 4.6 (1.6; range 1–14) days.

Psychosocial consequences of donation

The HRQoL course. Mean physical and mental HRQoL scores pre- and post-donation, as well as statistically significant and clinically relevant differences between the time points, are reported in Table 2.

Physical functioning. Physical HRQoL (RAND-SF36 Physical Component Score) did not significantly change from before to 12 months post-donation (Figure 2). Median scores were within 1 SD above population norms at all time points. For physical functioning, the percentage of donors showing a clinically relevant worsening was 7–15%, depending on the time frame, whereas 11–15% of donors showed a clinically relevant improvement.

Fatigue scores changed significantly over time, with higher fatigue levels at 6 ($P < 0.001$) and 12 ($P < 0.001$) months post-donation as compared with pre-donation, and comparable levels of fatigue at both post-donation assessments (Figure 3). Pre-donation fatigue scores were comparable to general population norms, but post-donation fatigue scores were 0.5 SD higher. For fatigue, the percentage of donors showing a clinically relevant worsening (11–35% of donors, depending on time frame) was two to three times higher than the percentage showing a clinically relevant improvement (6–12%).

Regarding the specific aspects of physical HRQoL (RAND-SF36 subscales), physical functioning changed significantly over time, with a decrease of functioning from before to 6 months post-donation ($P < 0.001$), and an increase to baseline from 6 to 12 months post-donation ($P = 0.001$). Also, role limitations due to physical health problems changed significantly over time, with an increase of role limitations from before to 6 months post-donation ($P < 0.001$), followed by a decrease from 6 to 12 months post-donation ($P = 0.049$). The resulting level at 12 months indicated still more role limitations than at baseline ($P < 0.001$). Furthermore, significant changes in general health perceptions were indicated, with worse general health perceptions pre-donation than at 6 ($P = 0.001$) and 12 months ($P = 0.002$) post-donation. No difference between both post-donation assessments was found. Pain did not significantly change over time.

Psychological functioning. Mental HRQoL (RAND-SF36 Mental Component Score) changed significantly over time ($P = 0.001$), with a decrease of functioning from before to 6 months post-donation ($P = 0.01$), and an increase from 6 to 12 months post-donation ($P = 0.001$) (Figure 2). Median scores were within 1 SD above population norms at all time points. Clinically

Table 1. Demographic characteristics and donor and recipient intra-operative and post-operative factors

Characteristics	Mean ± SD (range), *N* (%)
Baseline demographic characteristics	
Age (years)	55.1 ± 10.7 (23–76)
Gender (%)	
Female	59
Male	41
Marital status[a] (%)	
Single	19
Steady partner	81
Educational level[b] (%)	
Primary education	5
Secondary education	62
Tertiary education	33
Donation type (%)	
Direct	83
Kidney exchange procedure	8
Anonymous	9
Donor–recipient relationship (%)	
Spouse	30
Parent	20
Sibling	18
Child	3
Other—related	17
Other—unrelated	3
Anonymous	9
Religious affiliation[b] (%)	
Religious	53
Non-religious	47
Ethnicity (%)	
Dutch	95
Other	5
Donor intra-operative and post-operative characteristics	
Surgery type (%)	
Mini-incision donor nephrectomy	15
Laparoscopy	85
Hospital stay (days)	4.6 ± 1.6 (1–14)
Donor complications[c] (%)	
No complications	83
Grade I	9
Grade II	7
Grade III (i)	0
Grade III (ii)	1
Grade IV (i)	0
Grade IV (ii)	0
Grade V	0
Recipient complications	
Graft failure (%)	
No	94
Yes	6
Patient death (%)	
No	97
Yes	3

[a] $n = 228$.
[b] $n = 229$.
[c] Categorization according the Clavien–Dindo classification system; Grade I: no need for therapeutic interventions; Grade II: pharmacological treatment required; Grade III: surgical, endoscopic or radiological intervention required (i) not under general anaesthesia or (ii) under general anaesthesia; Grade IV: life-threatening complication requiring intensive care management for (i) single organ dysfunction or (ii) multi-organ dysfunction; and Grade V: patient death [22].

relevant improvements of psychological functioning were found in 13–20% of donors, and a clinically relevant worsening was found in 11–27% of donors.

Concerning the specific aspects of mental HRQoL, no overall time effects were found for emotional wellbeing and role limitations due to mental health problems. Energy levels changed significantly over time ($P < 0.001$), with higher energy levels before donation than 6 months post-donation ($P < 0.001$), which significantly increased from 6 to 12 months post-donation ($P = 0.001$) but remained marginally lower than before donation at 12 months post-donation ($P = 0.07$). Last, social functioning changed significantly over time ($P = 0.01$), with better functioning pre-donation than 6 ($P = 0.002$) and 12 ($P = 0.01$) months post-donation, with no significant difference between both post-donation assessments.

No differences on the outcomes were found between donors who completed all three assessments and donors who dropped out of the study.

Donor-perceived consequences of donation

The course of donor- and recipient-related functioning. The quality of the donor–recipient relationship did not change over time and was perceived very positively (86–92%). Donors reported that after transplantation, the physical and emotional functioning of their recipients markedly improved ($P < 0.001$), and they perceived fewer recipient limitations in daily life ($P < 0.001$). Also, the donor's life was less influenced by the recipient's kidney disease after transplantation ($P < 0.001$), with 59% of donors experiencing moderate–much influence pre-donation, and 29–33% 6 and 12 months post-donation. Lastly, donors felt less responsible for their recipient's wellbeing ($P < 0.001$) and donors took over fewer recipient's tasks than before transplantation ($P < 0.001$) (Table 3).

Perceived donation consequences. The scores on post-donation negative physical or relational consequences were low. Only 5% of donors had a score of 4 or more (on a 5-point scale) on negative physical consequences, and for negative relational consequences, this percentage was even lower (1%). The majority of donors reported positive recipient outcomes at 6 (80%) and 12 (82%) months after transplantation. Nevertheless, many (57–66%) donors reported some degree of post-donation worries (Table 4). Changes in donor-perceived consequences of donation over time were only found for physical consequences, which were perceived to a lesser extent at 12 than 6 months after donation ($P<0.003$) (Table 4).

Regret towards the donation decision. One-year post-donation, most donors had no to minimal feelings of regret about the donation decision (median = 5.0, interquartile range 0–20, on a 0–100 scale). Fourteen percent of the donors reported substantial feelings of regret. Because of the small number of donors experiencing regret ($n = 32$), differences between participants experiencing regret versus those who did not on HRQoL at the different time points were examined in an exploratory analysis. These preliminary analyses with regret showed no baseline HRQoL differences, but participants experiencing regret reported more negative health perceptions and worse social functioning at both 6 and 12 months after

Table 2. Descriptive statistics (mean ± SD) of donor self-report measures of HRQoL and fatigue

Donor self-report measures	Before donation	6 months after donation	Pre-donation versus 6 months after donation			12 months after donation	Pre-donation versus 12 months after donation			6 versus 12 months after donation		
	Mean ± SD (range)	Mean ± SD (range)	P-value	Clinically relevant difference (%)		Mean ± SD (range)	P-value	Clinically relevant difference (%)		P-value	Clinically relevant difference (%)	
				+	−			+	−		+	−
Health-related quality of life												
Physical HRQoL (RAND-SF36)												
Physical Health Composite Score[a]	55.6 ± 4.5 (34.0–61.0)	54.9 ± 7.0 (22.0–61.0)	0.55	11	15	55.5 ± 6.6 (22.0–61.0)	0.06	13	12	0.06	15	7
Physical Functioning[a]	55.7 ± 3.9 (27.0–58.0)	54.1 ± 5.7 (26.0–58.0)	<0.001	6	19	54.9 ± 5.7 (24.0–58.0)	0.20	10	16	0.001	12	7
Role Limitations—Physical Health[a]	55.0 ± 4.9 (26.0–56.0)	51.9 ± 9.0 (26.0–56.0)	<0.001	5	18	53.0 ± 7.8 (26.0–56.0)	<0.001	4	15	0.049	13	7
Pain[a]	56.9 ± 6.0 (25.0–60.0)	57.3 ± 6.4 (22.0–60.0)	0.26	19	13	57.4 ± 6.5 (22.0–60.0)	0.09	20	11	0.35	12	9
General health perceptions	53.3 ± 6.9 (36.0–64.0)	55.1 ± 7.3 (32.0–64.0)	0.001	36	19	55.0 ± 7.7 (29.0–64.0)	0.002	32	20	0.85	20	15
Fatigue (CIS short version)												
Fatigue[a]	7.0 ± 3.8 (4.0–26.0)	9.5 ± 6.1 (4.0–28.0)	<0.001	6	11	9.0 ± 6.0 (4.0–28.0)	<0.001	11	20	0.10	12	35
Psychological HRQoL (RAND-SF36)												
Mental Health Composite Score[a]	55.2 ± 6.5 (31.0–66.0)	53.4 ± 8.6 (25.0–66.0)	0.01	13	27	54.6 ± 8.5 (22.0–66.0)	0.66	18	21	<0.001	20	11
Emotional Wellbeing	53.1 ± 7.5 (28.0–66.0)	52.5 ± 8.8 (29.0–66.0)	0.25	16	25	53.6 ± 8.4 (27.0–66.0)	0.36	24	19	0.03	24	16
Role Limitations—Mental Health[a]	52.7 ± 5.2 (19.0–54.0)	51.4 ± 7.9 (19.0–54.0)	0.02	4	10	51.6 ± 8.0 (19.0–54.0)	0.07	5	9	0.69	9	6
Energy	56.8 ± 7.4 (35.0–70.0)	54.2 ± 8.8 (30.0–70.0)	<0.001	20	37	55.7 ± 8.8 (30.0–70.0)	0.07	21	26	0.001	31	16
Social Functioning[a]	54.3 ± 5.5 (31.0–57.0)	52.4 ± 7.9 (17.0–57.0)	0.002	14	25	52.9 ± 7.5 (20.0–57.0)	0.01	13	24	0.40	17	15

[a]Variable transformed in analyses because of no normal distribution.

+: Clinically relevant improvement; −: clinically relevant worsening, defined as 5-point differences in *T*-scores using the RAND-SF36 and 0.5 SD differences of norm scores using the CIS.

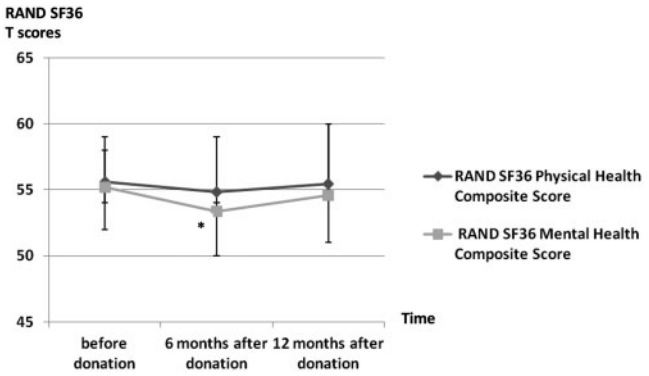

FIGURE 2: The course (means and interquartile range) of the physical and mental health composite scores of the RAND SF36 before, 6 and 12 months after donation [*T*-values, with mean (SD) scores of 50 (10) in the general population]. *Significant at P<0.05 level in comparison with baseline level.

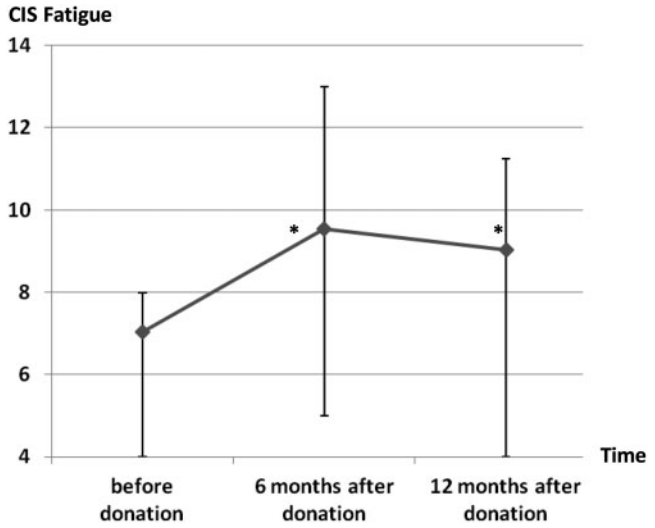

FIGURE 3: The course (means and interquartile range) of fatigue (CIS) before, 6 and 12 months after donation. *Significant at P<0.05 level in comparison with baseline level.

donation. These findings need to be backed up by a larger subgroup of donors.

Higher levels of regret were associated with different pre-donation factors, namely worse emotional functioning of the recipient ($r = -0.15$), more donor feelings of responsibility about the recipient ($r = 0.15$), higher expectations about donor benefits ($r = 0.16$), more anxiety ($r = 0.17$) and lower age ($r = -0.14$). Also, more influence of the recipient's transplantation on the donor's life ($r = 0.18$), worse health perceptions ($r = -0.15$), worse social functioning ($r = -0.14$) and worse surgery recovery ($r = -0.37$) 6 months post-donation were related to more regret 12 months post-donation. No significant relationships between regret and different donation types or donor–recipient relationships were found. From multiple regression analyses, worse health perceptions ($\beta = -0.21$, $P = 0.02$) and worse social functioning ($\beta = -0.23$, $P = 0.04$) 6 months post-donation were significant predictors of more regret 12 months post-donation, while no significant predictors on baseline were found.

Fatigue after donation

Because a clinically relevant worsening of fatigue was found in up to 35% of donors at the longer term after donation, baseline predictors of fatigue 6 and 12 months after donation were examined. Significant predictors of more fatigue 6 months after donation were higher levels of baseline fatigue ($\beta = 0.37$, $P < 0.001$), worse baseline physical functioning ($\beta = -0.25$, $P = 0.001$), younger age ($\beta = -0.21$, $P = 0.004$), longer hospital stay after the surgery ($\beta = -0.18$, $P = 0.005$) and more influence of the recipient's functioning on the donor's life before donation ($\beta = 0.18$, $P = 0.01$). Higher levels of fatigue 12 months after donation were only predicted by more baseline fatigue ($\beta = 0.19$, $P = 0.04$).

DISCUSSION

The current study examined psychosocial consequences of donation, including the course of HRQoL and donor- and recipient-related donation consequences from the donor's perspective. Donor physical and mental HRQoL were largely comparable at all time points. There was a temporary decrease for some aspects of physical and psychological functioning at 6 months post-donation, but most levels had returned to baseline at 12 months post-donation. Also, scores were above population norms at all time points. Persistent and clinically relevant changes were only found for fatigue, which increased post-donation up to 1 year. Strongest predictors of higher fatigue levels after donation were worse pre-donation fatigue or more general physical functioning and a younger age. Fourteen percent of donors indicated regret about the donation decision 12 months after donation. Predictors of regret were more negative health perceptions and worse social functioning 6 months after donation. The donors reported a low rate of negative donation consequences concerning themselves, the recipients or their relationship with the recipient. Instead, they perceived a strong improvement in recipient's functioning and a reduced influence of the kidney disease on their own life.

The stability of physical functioning over time indicates that most donors are physically recovered from surgery during the first months post-donation, as was found in previous studies [2, 28]. However, complaints of fatigue persisted in the longer term, indicating that fatigue is the aspect of physical functioning that is mostly affected by donation, which is in line with the conclusion from our meta-analysis on HRQoL consequences of kidney donation [2]. Potential causes of these elevated fatigue levels are currently unknown, with not only physical (surgery consequences) but also behavioural or cognitive causes being possible (donation or recipient worries, or regret) [29]. The current study is the first to identify potential predictors of longer term fatigue after donation, with pre-donation fatigue and physical functioning being the strongest predictors that could be impacted by means of interventions. More research on predictors of fatigue is necessary to enable the development of validated screening instruments and treatments. The temporary

Table 3. Descriptive statistics (VAS scores 0–10; means ± SD) of donor-reported judgements of donor–recipient interaction

Donor reported judgements	Before donation		6 months after donation		Pre-donation versus 6 months after donation P-value	12 months after donation		Pre-donation versus 12 months after donation P-value	6 months versus 12 months after donation P-value
	Means ± SD (range)	%	Means ± SD (range)	%		Means ± SD (range)	%		
Physical functioning of the recipient[a]	4.8 ± 2.0		7.6 ± 1.9		<0.001	7.7 ± 1.8		<0.001	0.88
Poor (0.0–0.4)	(0.4–10.0)	1	(0.0–10.0)	2		(0.0–10.0)	1		
Fair (0.5–4.4)		44		4			4		
Moderate (4.5–7.4)		45		32			27		
Good (7.5–10.0)		10		62			68		
Emotional wellbeing of the recipient[a]	6.6 ± 1.7		7.9 ± 1.7		<0.001	7.9 ± 1.9		<0.001	0.81
Poor (0.0–0.4)	(1.5–10.0)	0	(0.0–10.0)	2		(0.0–10.0)	1		
Fair (0.5–4.4)		13		1			4		
Moderate (4.5–7.4)		51		27			21		
Good (7.5–10.0)		36		70			74		
Limitations for the recipient caused by the kidney disease or transplantation[a]	4.4 ± 2.2 (0.0–10.0)		6.9 ± 2.1 (0.0–10.0)		<0.001	7.4 ± 1.9 (0.0–10.0)		<0.001	0.04
Many (0.0–0.4)		2		2			1		
Some (0.5–4.4)		52		10			7		
Few (4.5–7.4)		36		37			31		
No (7.5–10.0)		10		51			61		
Quality of the donor–recipient relationship[a,b]	8.7 ± 1.1 (3.0–10.0)		8.5 ± 2.0 (0.0–10.0)		0.24	8.7 ± 1.6 (0.0–10.0)		.97	0.27
Poor (0.0–0.4)		0		3			1		
Fair (0.5–4.4)		1		2			1		
Moderate (4.5–7.4)		7		9			8		
Good (7.5–10.0)		92		86			90		
Influence of the recipient's kidney disease on the life of the donor[c]	4.9 ± 2.8 (0.0–10.0)		3.2 ± 3.0 (0.0–10.0)		<0.001	2.9 ± 3.0 (0.0–10.0)		<0.001	0.04
No (0.0–0.4)		8		16			18		
Little (0.5–4.4)		33		51			53		
Moderate (4.5–7.4)		37		17			15		
Much (7.5–10.0)		22		16			14		
Donor feelings of responsibility for the wellbeing of the recipient[c]	5.6 ± 3.1 (0.0–10.0)		4.1 ± 3.2 (0.0–10.0)		<0.001	4.3 ± 3.5 (0.0–10.0)		<0.001	0.85
No (0.0–0.4)		9		11			15		
Few (0.5–4.4)		23		42			34		
Some (4.5–7.4)		33		23			24		
Many (7.5–10.0)		35		24			27		
Donor taking care of recipient tasks that cannot be accomplished due to the kidney disease[c]	2.6 ± 3.0 (0.0–10.0)		1.6 ± 2.4 (0.0–10.0)		<0.001	1.4 ± 2.1 (0.0–9.0)		<0.001	0.32
No (0.0–0.4)		36		34			40		
Little (0.5–4.4)		36		50			48		
Moderate (4.5–7.4)		18		10			8		
Many (7.5–10.0)		10		6			4		

[a]Higher scores represent higher wellbeing.
[b]Variable transformed in analyses because of no normal distribution.
[c]Higher scores represent lower wellbeing.

Table 4. Descriptive statistics (means ± SD) of donor-reported judgements of perceived donation consequences and regret

	6 months after donation		12 months after donation		6 versus 12 months post-donation P-value
	Means ± SD (range)	%	Means ± SD (range)	%	
Perceived donation consequences (Perceived Donation Consequences Scale)[a]					
Negative physical consequences	2.1 ± 0.9 (1.0–4.8)		2.0 ± 0.9 (1.0–5.0)		0.003
In retrospect, the surgery was worse than anticipated		No/few 47		No/few 57	
I still frequently experience physical symptoms like pain and fatigue due to the donation		Some 48		Some 39	
My recovery from surgery took longer than I expected		Many 5		Many 4	
I have not been able to resume all my day-to-day routines					
The physical effects of the donation were greater than I expected					
Post-donation worries	2.1 ± 0.7 (1.0–3.8)		2.1 ± 0.7 (1.0–4.2)		0.28
I found it difficult to get used to the idea that I only have one kidney		No/few 34		No/few 42	
I still find myself quite preoccupied by the donation		Some 66		Some 57	
I am concerned about the performance of my remaining kidney in the future		Many 0		Many 1	
I am concerned about how the kidney I donated will function in the future					
I am finding it difficult to let go of my care for the recipient after the donation					
Positive recipient consequences	4.2 ± 0.8 (1.0–5.0)		4.3 ± 0.7 (1.0–5.0)		0.64
The quality of life of the recipient has improved due to the donation		No/few 2		No/few 2	
The disease burden of the recipient in daily life has been reduced		Some 18		Some 16	
The risks for the recipient as a consequence of the kidney disease have been reduced due to the donation		Many 80		Many 82	
Negative relational consequences	1.5 ± 0.6 (1.0–4.4)		1.5 ± 0.6 (1.0–5.0)		0.72
Relations within the family/with my partner have changed for the worse since the donation					
My relationship with the recipient has changed for the worse due to the donation		No/few 79		No/few 78	
The relationship with the recipient has been put under pressure		Some 20		Some 21	
I expected more appreciation and attention from the recipient		Many 1		Many 1	
My relationships with relatives of the recipient have changed for the worse due to the donation					
Regret about the donation decision (Decision Regret Scale)[b]					
Decisional regret			12.2 ± 21.8 (0–100)		
No feelings of regret (<30)				86	
Substantial feelings of regret (≥30)				14	

[a]Higher scores represent more donor consequences.
[b]Higher scores represent more decisional regret.

decrease of mental HRQoL 6 months post-donation might be the consequence of the resumption of daily life activities after surgery, which could lead to a higher physical and mental burden. Furthermore, donors mostly received a lot of attention during the donation procedure, both from the hospital and relatives. However, afterwards, attention for donors diminishes or shifts back to the recipient, and everything is expected to be back to normal [15, 30]. Therefore, opportunities for sharing donation experiences or potential worries and feelings of social support could decrease, which could potentially lead to a poorer mental HRQoL.

Whereas most previous studies have focused primarily on the course of generic HRQoL after kidney donation, the current study included a broad range of donation-specific psychosocial consequences, including donor-perceived consequences for both donor and recipient and their relationship, post-donation worries and regret. In line with previous studies, donation experiences were mainly positive, with small

percentages of donors (0–5%) reporting negative physical and relational consequences and post-donation worries. The percentage of donors experiencing a substantial level of regret 1-year post-donation found in the current study (14%) is higher than the levels that were found in previous studies. However, it is comparable to percentages reported in a systematic review on decision regret with regard to different kinds of healthcare decisions. Potentially, the use of a quantitative multidimensional measurement of regret (the Decision Regret Scale) could provide other information about the extent to which donors experience regret. In line with the previous study on post-donation doubts about the donation [5], in the current study, more regret was associated with different demographic and recipient-related factors, and lower HRQoL. However, in the current study, donation type and donor–recipient relationship were not significant predictors of regret after donation. Because no pre-donation predictors but only more negative health perceptions and worse social functioning 6 months after donation predicted longer term regret, post-donation monitoring seems indicated to provide interventions to high-risk donors to prevent the onset or deterioration of regret after donation. Furthermore, as it was found that regret could change over time [20], it would be relevant to examine whether donor regret persists or abates in the long-term.

Donors reported improvements of recipient's physical and emotional functioning after transplantation, which reflect a desired donation outcome, which is often a major motivation to donate. This improvement of recipient's HRQoL was also, and perhaps more objectively, confirmed by the decreased influence of the recipient's kidney disease on the donor's life. Although the increase of recipient's HRQoL after kidney transplantation is known from previous studies [31, 32], the donor's perspective hereon had not been prospectively studied before. Also, the influence of recipient's kidney disease on the donor's life, both before and after donation, is a relatively a new theme in transplantation literature because most studies specifically focus on the influence of recipient graft failure or death.

A small proportion of donors experienced negative donation consequences (decreased HRQoL, adverse effects on the donor–recipient relationship or regret). Future research should identify risk factors of donor's HRQoL after donation and develop interventions for (potential) donors at risk. Furthermore, in order to prevent unrealistic expectations, consultations of healthcare professionals with potential donors should focus on evidence-based information regarding the potential consequences of kidney donation, discussion of alternative treatment options, expectations of the transplantation for the recipient and on the preferences and values of the potential donor.

This multicentre study in a large and representative population of kidney donors gives insight into psychosocial consequences of kidney donation, including the course of HRQoL from before to 12 months post-donation, and evaluates donor-perceived consequences of donation with regard to their own, recipient and mutual functioning. Ideally, a study like this one should include a relevant control group. However, a comparable control group of eligible donors who eventually do not donate was not available. Instead, HRQoL results were compared with population norms, and clinically relevant differences between time points were assessed to frame results. The group of donors whose recipient experienced graft failure or death was very small (3–6%), which is a very good outcome, but complicates the reliable assessment of the influence of recipient complications on donor's HRQoL course. Future research should examine long-term psychosocial consequences of donation. Most donors included had Dutch nationality. Also, the healthcare setting of kidney donors in the Netherlands, in terms of access to care and regulations for health insurance, is well-organized and available to all inhabitants. Therefore, the generalization of findings has to be studied.

In conclusion, for most donors, the donation procedure has few negative psychosocial consequences. Concerning HRQoL changes, small temporary decreases returned to baseline within 1-year post-donation and scores remained at or above population norms. The clinically relevant and persistent impact of donation on fatigue, which has been previously reported, warrants specific attention. The fact that a small subgroup of donors was found to experience negative HRQoL consequences underlines the relevance for further research into predictors of these outcomes, which would enable improved screening and potential interventions in those at-risk donors.

SUPPLEMENTARY DATA

Supplementary data are available at ndt online.

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CONFLICT OF INTEREST STATEMENT

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