Transplant International

ORIGINAL ARTICLE

# Psychosocial wellbeing after living kidney donation – a longitudinal, prospective study

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## SUMMARY

Living kidney donation (LKD) has become routine practice across the world as the gold standard treatment of end-stage renal failure. Whilst the physical risks and harms of LKD surgery are well documented, relatively little is known about psychosocial outcomes. The aim of this study was to determine whether it was possible to quantify the psychosocial impact of LKD. A prospective longitudinal study of 93 living kidney donors was performed. Data were collected preoperatively, and 3 and 12 months after donation. Questionnaires included 11 validated psychosocial outcome measures and questions specific to LKD. Over time, there was no significant change in wellbeing, life satisfaction, self-esteem, social comparison, distress, depression, stress, anxiety or social support at 3 or 12 months. Despite this, questions specific to LKD indicated that donors felt positively about donation, with low levels of regret. This study provides a thorough assessment of psychosocial outcomes after LKD over the first year. Donors felt positive about LKD although there was no evidence of any significant change in psychosocial outcomes. Despite no measurable psychosocial benefit after living kidney donation, there was also no evidence of harm.

*Transplant International* 2017; 30: 987–1001

**Key words**
living kidney donation, psychosocial, quality of life, wellbeing

Received: 6 November 2016; Revision requested: 12 December 2016; Accepted: 21 April 2017;

## Introduction

Living kidney donation (LKD) has become routine practice across the world as the gold standard treatment of end-stage renal failure. Whilst the physical risks and harms of LKD surgery are well known, relatively little is understood about the psychosocial outcomes. There are a number of papers that have attempted to further appreciate the psychosocial aspects of LKD. The qualitative literature has addressed donor psychosocial outcomes in considerable detail, due to the very nature of how these studies are conducted and the types of data they generate. Studies have focussed on many different aspects, such as decision-making, expectations and the opinions of transplant professionals [1–6]. They have also identified concerns regarding donor mental health and whether the benefits of donation outweigh the risks [7–11]. LKD is often described as a complex topic, with multiple interplaying issues that all affect psychosocial outcomes.

The quantitative literature is comparably less detailed; however, the studies are more numerous and rely on a mixture of validated and nonvalidated questionnaires [12]. They demonstrate that high proportions of donors experience no change in their relationship with their recipient, no depression and no anxiety. Donors report feeling proud, heroic and brave, and the majority do not regret their decision

doi:10.1111/tri.12974

to donate. There does not appear to be a higher incidence of psychiatric problems within the donor population; however, donor suicides have been reported [10]. Health-related quality of life (HRQoL) is by far the most measured concept within the quantitative literature, and outcomes are variable [12]. Negative psychosocial outcomes are more commonly reported in prospective studies (i.e. reduced HRQoL [14–21] and increased depression and anxiety after donation [22,23]) and include feelings of abandonment, being ignored and disappointment [12]. Poor outcomes in the recipient are associated with increased rates of depression and lower HRQoL [17,24–26].

Although the results discussed above are predominantly positive, they must be interpreted with some caution due to the poor quality of some of the studies conducted. Methodological issues include the paucity of pertinent information in some, such as the method of recruitment, eligibility criteria and reasons for loss of follow-up. Studies are commonly retrospective, with small sample sizes and variable response rates, which may have resulted in spurious and inaccurate conclusions or type 2 statistical errors. Questionnaire studies were also commonly quite simple, measuring just one psychological concept at a single time point.

What transplant clinicians are therefore faced with is a lack of congruence within the literature. The complex, multifaceted topic as described within qualitative studies is a stark contrast to the relatively simple quantitative studies which often aim to explore a single concept rather than the spectrum of different, interplaying issues inherent to living donation [11]. This has resulted in a deficit in quantitative data, with very few studies attempting to prospectively quantify the psychosocial impact of living donation in the level of detail required. There are therefore limited data available to help clinicians advise donors on their likely psychosocial outcome after LKD.

The aim of this study was to determine whether it was possible to quantify the psychological impact of LKD through the utilization of well-established psychosocial outcome measures. We conducted a comprehensive quantitative assessment of LKD, utilizing a broad range of questionnaires, in an attempt to bridge the gap between the qualitative and quantitative literature. A quantitative design was adopted so to provide clinicians with reliable quantitative data on LKD psychosocial outcomes, akin to the data presented to living donors regarding physical outcomes.

## Materials and methods

### Design and materials

A prospective longitudinal study of living kidney donors was performed. Data were collected at three time points: preoperatively, and 3 and 12 months after donation. These time points were used to assess the difference between pre- and postoperative scores and to assess the impact of living donation across both the short- and long-term recovery period. The short-term recovery period selected was 3 months as this marks the end of the recommended convalescence period as outlined in the UK national guidelines [27] and is typically when donors return to work and normal activities. The long-term recovery period selected was 12 months because this marks the start of the annual review process and is a time by which donors are usually expected to have made a full physical recovery. The questionnaire comprised two sections. Section A included 11 validated psychosocial outcome measures that were used to capture data on different psychosocial factors (Table 1). Each validated questionnaire was selected based on its psychometric properties. Validated abbreviated versions were used whenever possible to reduce responder burden.

### Questionnaire validation

Section B included newly developed questions specific to LKD. These were written by the research team and underwent face, content and construct validity testing, and reliability testing [28] (Table 2). These demonstrated statistically significant medium or large correlations against the anxiety, self-esteem and social support questionnaires listed in Table 1. Opportunities to perform internal consistency tests were limited; however, when done so, they demonstrated an acceptable level of internal consistency (Cronbach's alpha = 0.747). The test–retest reliability results were obtained by asking a sample of 30 donors to complete the three-month questionnaire on two occasions, 2 weeks apart. These results demonstrated a medium or large correlation (Table 2) indicating satisfactory test–retest reliability for these items.

### Participants

All potential adult living kidney donors due to donate at our centre between August 2012 and August 2013 were eligible for inclusion. An information leaflet was

**Table 1.** Psychosocial factors measured and the validated questionnaire selected.

| Psychosocial factor | Validated questionnaire | Questionnaire details |
|---|---|---|
| Wellbeing | Office of National Statistics Wellbeing questions [45] | Developed as part of the UK Measuring National Wellbeing Programme<br>Includes 4 items capturing data on life satisfaction, happiness, worry and worthwhileness<br>Each item is answered on an 11-point scale, ranging from 0 to 10. Item 3 (worry) is reverse-scored<br>Range of scores = 0–40; higher scores indicate higher personal wellbeing. UK average score = 29.5 [46] |
| Distress | General Health Questionnaire-12 (GHQ-12) [47] | Abbreviated version of the 60-item original; designed to detect current diagnosable psychiatric disorders<br>Each question has 4 possible answers which are coded as per a Likert scale (0–3)<br>Range of scores = 0–36; higher scores indicate more distress. Average score quoted by the authors = 11–12 |
| Mood | Patient Health Questionnaire-2 (PHQ-2) [48] | Abbreviated version of the 9-item full version<br>Intended to be used a depression screening tool. It enquires about the frequency of depressed mood and anhedonia over the preceding 2 weeks<br>Each question has 4 possible answers which are coded 0–3<br>Range of scores = 0–6; higher scores indicate worse mood<br>A PHQ-2 score of 3 or greater can be used to as a cut-off score for potential clinical depression |
| Stress | 4-item Perceived Stress Scale (PSS) [49] | Used to measure the degree to which situations in one's life over the preceding month are viewed as stressful<br>Each question has 5 possible answers scored 0–4. Items 2 and 3 are reverse-scored<br>Range of scores = 0–16; higher scores indicate more perceived stress. Average score quoted by the authors = 4.5 |
| Physical Health-Related Quality of Life | Short Form-12 (Physical components only) [50] | The Short Form measures are well-established generic measures of health-related quality of life and have been used extensively within healthcare and within the living donor population<br>The physical component questions of the Short Form-12 were included in the questionnaire to capture data on the physical aspects of quality of life*<br>All 7 physical component questions from the SF-12 were included. They enquire about a participant's ability to perform simple day to day activities<br>Questions were scored 1–3 or 1–5, depending on the question<br>Range of scores = 7–31; higher scores indicate higher physical health-related quality of life |
| Life satisfaction | Satisfaction With Life Scale (SWLS) [51] | Questionnaire was developed to assess satisfaction with the respondent's life as a whole, allowing subjects to weight the different domains that may determine life satisfaction in whichever way they choose<br>Includes 5 items which are scored on a 7-point Likert scale (1–7)<br>Range of scores = 5–35; higher scores indicate higher life satisfaction. Average range = 23–28 [52] |
| Self-Esteem | Rosenberg Self-esteem Scale [53] | Measures global self-worth by measuring both positive and negative feelings towards oneself<br>10 items which are scored on a 4-point Likert scale (0–3); items 2, 5, 6, 8 and 9 are reverse-scored<br>Range of scores = 0–30; higher scores indicate higher self-esteem. Average score = 15–25 |
| Anxiety | 6-item State-Trait Anxiety Inventory (STAI-6) [54] | Abbreviated version of the 40-item original, which was designed to measure the presence and severity of current symptoms of anxiety [55]. The 6-item version measures state anxiety only, that is a temporary state of anxiety which is related to how the individual is feeling at the time [56]<br>Each question is answered on a 4-item Likert scale (1–4); questions 1, 4 and 5 are reverse-scored<br>Range of scores = 6–24; higher scores indicating higher state anxiety. No normal range or average score available |
| Social support | Multidimensional Scale of Perceived Social Support (MSPSS) [57] | Measures perceived social support from three sources: family, friends and significant others<br>12 questions. Each answered on a 7-point Likert scale (1–7)<br>Range of scores = 12–84; higher scores suggest a higher degree of perceived social support. No normal range or average score available |

**Table 1.** Continued.

| Psychosocial factor | Validated questionnaire | Questionnaire details |
|---|---|---|
| Optimism | Life Orientation Test – Revised (LOT-R) [58] | Abbreviated version of the 12-item original; measures optimism or, more specifically, a person's expectations regarding the favourability of future outcomes<br>10 items, answered on a 5-point scale (0–4). Four items are fillers and are not used in scoring. Items 3, 7 and 9 are reverse-scored<br>Range of scores = 0–24; higher scores indicate higher optimism |
| Social comparison | Social comparison scale [59] | 11-item scale; developed to measure self-perceptions of social rank and relative social standing<br>Participants are required to make a global comparison of themselves in relation to others<br>Asks participants to complete the sentence 'In relationship to others I generally feel. . .' by putting a mark on a 10-point scale which is anchored at each end with 10 bipolar constructs, such as inferior–superior, incompetent–more competent and unlikeable–more likeable<br>Range of possible scores is 11–110; high scores indicate feelings of superiority and generally high rank self-perceptions. No normal range or average score available |

*Mental component questions were removed as other questionnaires measuring psychological factors were being used throughout the questionnaire and there was a desire to reduce responder burden as much as possible.

provided prior to recruitment, and written informed consent was obtained before questionnaires were distributed. Those who did not respond to initial contact received two reminders. Ethical approval was obtained (09/H0804/31). Participants were recruited during their final preoperative hospital visit 2–4 weeks prior to donation, once full approval had been granted and a date for surgery set.

### Statistical methodology

IBM SPSS version 22 was used for all statistical analyses. Normality of the data was assessed by visual inspection of graphs and numerically through the use of the Shapiro–Wilk test on occasions where distribution was not clear. Independent-samples *t*-tests and one-way analysis of variance (ANOVA) were used to test between independent groups on occasions when the data were normally distributed. Mann–Whitney and Kruskal–Wallis tests were used to test between independent groups on occasions where the data were not normally distributed. Pearson and Spearman correlations were used for correlating two continuous variables for parametric and nonparametric data, respectively. Linear mixed models were used to assess any changes in psychosocial variables over time. In these models, time was a fixed factor with patient ID and the intercept set as random factors. All models were estimated using maximum-likelihood estimation.

## Results

### Recruitment

Over the study period, 115 individuals successfully completed a living donor assessment and were eligible for inclusion in the study (Fig. 1). Data were obtained from 100 participants (response rate = 87.0%) with ninety-three going on to donate a kidney. Six participants did not donate a kidney due to newly diagnosed physical health problems in either themselves or their intended recipient inbetween questionnaire completion and the proposed operation day. One participant withdrew consent for donation. All available data were used for analysis.

Seventy-seven participants completed questionnaires at all three time points (17.2% were lost to research follow-up; however, all were known to be still alive and physically well 12 months after donation). Demographic factors were analysed alongside questionnaire completion rates, and the only variable that was associated with

**Table 2.** Questions specific to donation and transplantation, including test–retest reliability scores.

| Question Theme | Question | *r* Value | *P* value |
|---|---|---|---|
| Feelings towards donation | I feel good about being a kidney donor | 0.590 | 0.004* |
| How donation compares to other life events | Donating a kidney is one of the best things I have ever done | 0.780 | <0.001* |
| Current regret | If I had my time again I would not choose to be a Living Kidney Donor | 0.692 | <0.001* |
| Anticipated regret | I will continue to feel the same way about being a Living Kidney Donor regardless of what happens in the future | 0.495 | 0.016* |
| Attitudes of others towards donor and the importance of receiving praise | I have been praised for being a Living Kidney Donor | 0.901 | <0.001* |
| | Being praised for being a Living Kidney Donor is not important to me | 0.446 | 0.033* |
| Effect on self-esteem | Being a Living Kidney Donor has improved my self-esteem (how I see myself) | 0.884 | <0.001* |
| Effect on life perception | Being a Living Kidney Donor has changed my outlook on life | 0.770 | <0.001* |

*$P < 0.05$.

postoperative questionnaire completion was ethnicity, with non-White participants less likely to complete a follow-up questionnaire at both 3 and 12 months (96% White vs. 53% non-White; $P < 0.001$; 87% White vs. 65% non-White; $P = 0.029$, respectively). There was no statistically significant difference in preoperative questionnaire scores between postoperative responders and nonresponders.

Participant hospital records were interrogated alongside researcher notes to establish potential reasons for loss to follow-up. In the majority of cases, no clear cause could be ascertained. The recipients of two nonresponders were known to have suffered complications (debilitating stroke and death from multi-organ failure). Two donor–recipient relationships broke down within the first month after donation. One was a UK-based donor who completed the three-month questionnaire, but failed to complete the 12-month questionnaire. The second was from overseas and completed no postoperative questionnaires.

## Demographic and clinical data

Table 3 outlines the demographic details of the 100 participants who completed a preoperative questionnaire. Six were from overseas, donating to UK-based recipients. The preoperative questionnaire was completed, on average, 11 days prior to surgery (IQR = 7). The three-month questionnaire was completed 97 days after donation (IQR = 14) and the 12-month questionnaire 367 days after donation (IQR = 9). Table 4 outlines medical, surgical and mental health histories, smoking status, BMI and pre- and postoperative blood results. Of note, formal psychological assessment of donors is not mandatory in the UK and is only done so if issues are identified.

Twenty-seven participants disclosed a history of mental health illness including depression (including nervous breakdown, postnatal depression and a suicide attempt) ($n = 22$), anxiety (including panic attacks) ($n = 8$) and a stress disorder ($n = 1$). Six were taking antidepressant medications at the time of donation. Table 5 outlines the transplant details and recipient demographics.

## Associations with preoperative psychosocial measures

Age, religious beliefs, level of education, employment status and relationship status were not associated with statistically significant differences with any of the preoperative psychosocial questionnaire scores. Preoperative distress was higher in White participants ($n = 79$, $M = 10.9$, SD = 4.36) than in non-White participants ($n = 15$, $M = 6.4$, SD = 6.47) [$P < 0.001$, 95% CI mean difference (−6.85, −2.10)]. Preoperative social comparison scores were lower in White participants ($n = 80$, $M = 66.45$, SD = 15.886) when compared to non-White participants ($n = 17$, $M = 78.47$, SD = 14.081) [$P = 0.005$, 95% CI (−20.290, −3.751)]. Previous medical or surgical history was not associated with differences in any of the validated questionnaire scores preoperatively, or at 3 or 12 months. Those with a previous history of mental health problems ($n = 27$) were found to have lower preoperative self-esteem [21.1 (SD = 5.41) vs. 23.2 (SD = 4.17); $P = 0.042$, 95% CI (0.075, 4.237)] and lower social support [63.20 (SD = 16.60) vs. 71.75 (SD = 9.21); $P = 0.002$]. Donating to a blood- or tissue-type-incompatible recipient

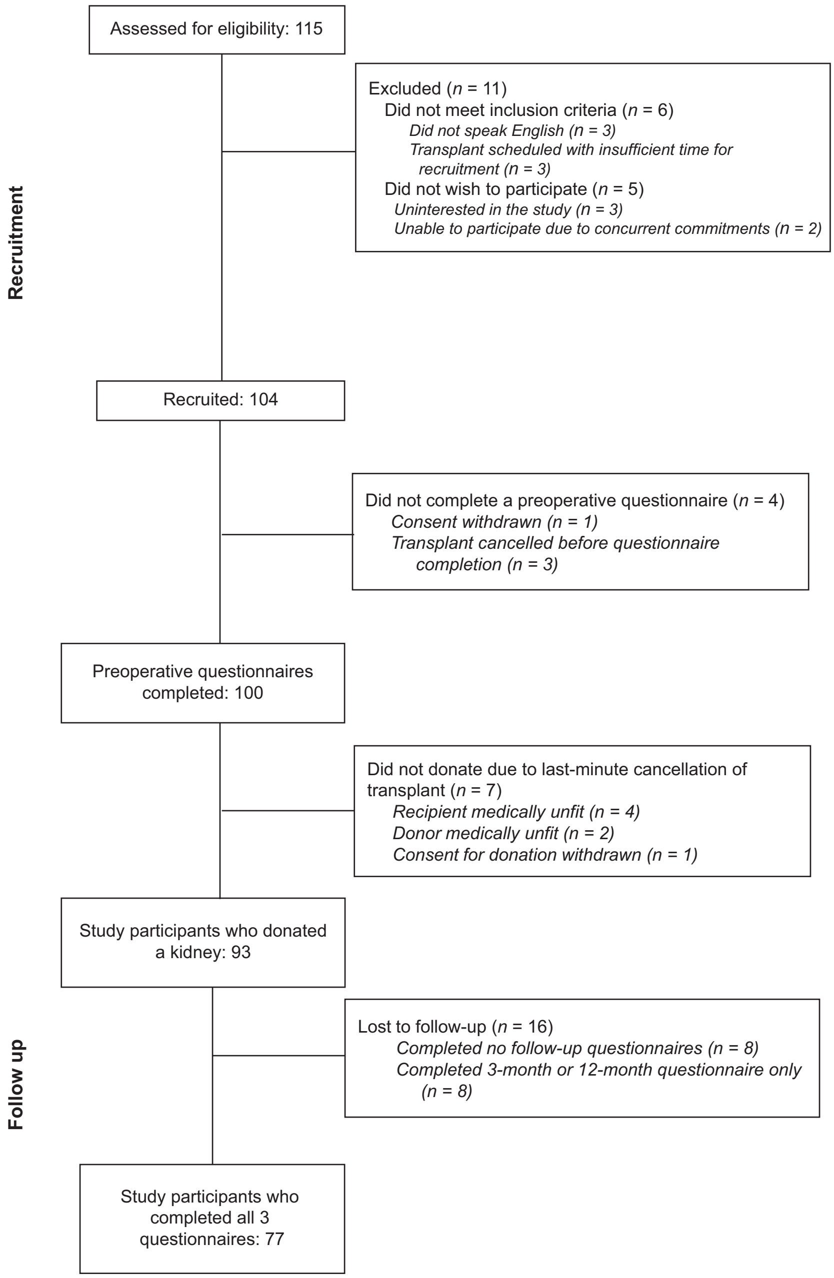


**Figure 1** Participant enrolment diagram.

was associated with higher preoperative distress [12.3 (SD = 4.61) vs. 9.7 (SD = 4.40); $P = 0.032$] and higher preoperative anxiety [12.9 (SD = 4.34) vs. 10.10.2 (SD = 3.70); $P = 0.006$] when compared to donating to a compatible recipient. As expected, all psychosocial variables preoperatively showed logical and significant intercorrelations, in the expected direction (Table 6).

## Trajectories of psychosocial outcomes over time: linear mixed models

A series of mixed models were evaluated to examine changes over time with regard to the psychosocial outcomes. The estimated model means at each time point are shown in Table 7. There was no main effect of time with regard to any of the psychosocial outcomes, with the exception of SF-12 physical component score. There was a significant overall effect of time ($F = 19.7$, $P < 0.01$), with participants showing a significant reduction in physical HRQoL at 3 months (model estimate = −2.4 95% CI −3.3, −1.5, $P < 0.05$). At 3 months, SF-12 scores were significantly lower compared to preoperative (mean difference = 3.28, $P < 0.01$) and 12-month scores (mean difference = 2.40, $P < 0.01$). Preoperative and 12-month SF-12 scores did not differ significantly (mean difference = 0.87, $P = 0.07$).

**Table 3.** Demographic data.

| Variable | Statistic (*n* = 100) |
|---|---|
| Gender | |
| Male | 55 |
| Female | 45 |
| Mean age at donation (years (SD)) | 45.0 years (12.98) |
| Ethnicity | |
| White | 82 |
| Non-white | 18 |
| Religious beliefs | |
| No religious beliefs | 35 |
| Christian | 54 |
| Muslim | 3 |
| Hindu | 2 |
| Buddhist | 1 |
| Other | 2 |
| Highest qualification | |
| No qualifications | 11 |
| School leaver | 17 |
| College level | 24 |
| Higher education | 42 |
| Other | 2 |
| Employment status | |
| Not currently working | 5 |
| Employed/in education | 65 |
| Self-employed | 17 |
| Retired | 7 |
| Other | 4 |
| Relationship status | |
| Single | 22 |
| Married or long-term partner | 70 |
| Divorced/separated | 7 |

The change in SF-12 over time was not associated with gender, HLAi compatibility, history of surgical procedures, history of mental health issues, preoperative eGFR or BMI. Age showed a significant interaction with time ($F = 4.53$, $P < 0.01$), with a 1-point increase in age associated with a small (estimate = 0.11, SE = 0.04, $P = 0.01$) increase in physical quality of life score at 3-month follow-up. The only other factor associated with the change in SF-12 score was length of hospital stay ($F = 2.8$, $P = 0.047$). For every day spent longer in hospital, there was an associated reduction in SF-12 score by 0.87 (SE = 0.31, $P < 0.01$) at 12 months.

### Point prevalence of potential depression using a PHQ-2 score of ≥3

Although no diagnostic measures were used, a PHQ-2 cut-off score of ≥3 is commonly employed to indicate *possible* clinical depression. At baseline, 4.1% (95% CI 0.1, 9.6) of the sample met this criteria. The prevalence of donors with a PHQ-2 cut-off score ≥3 at 3 and 12 months was 5.5% (95% CI 1.4, 12.3) and 11.6% (5.5, 19.2), respectively. The observed increase in prevalence was not statistically significant. Two patients had PHQ-2 cut-off scores ≥3 at all time points. Six patients who did not meet the cut-off score at baseline did at the 12-month follow-up.

### Documented postoperative psychological issues

This study had insufficient numbers to detect differences related to transplant failure ($n = 2$) and recipient death ($n = 1$), so these factors were analysed alongside all other recipient complications. At 3 months, 23 participants (26.1%) stated that their recipient had suffered a complication. There was no statistically significant difference in any of the three-month psychosocial questionnaire scores between those whose recipients had and had not suffered a complication. At 12 months, a further 15 participants (17.0%) stated that their recipient had suffered a complication. Those participants whose recipients had suffered a complication were found to be lower in mood than those whose recipients had not suffered a complication (1.18 vs. 0.59; $P = 0.031$); however, this small difference is unlikely to represent a clinically significant difference.

Five participants (5.4%; two female, three male) had postoperative psychological issues documented in their medical notes. Four were parental donors (three paediatric, one adult recipient), and one donated to a spouse. Documented issues included low mood ($n = 2$), increased anxiety related to the recipient's health ($n = 2$), increased anxiety when attending the hospital ($n = 1$; recipient deceased), feelings of guilt ($n = 2$), difficulty coping ($n = 1$) and anger management difficulties ($n = 1$). Six participants (6.5%) were offered a referral to a clinical psychologist. Four had reported psychological issues to the clinical team as noted above, and an additional two were referred following disclosure that their relationship with their recipient had deteriorated after donation. Of these, two were seen by a psychologist (1F, 1M), three were made appointments but did not attend (one female, two male) and one donor declined referral.

### LKD questions

The results of the donation specific questions are displayed in Fig. 2. The majority felt good about being a donor and felt that donating a kidney was one of the best things they had ever done. The answers to these questions at both postoperative time points were not significantly associated with any demographic factors, donor–recipient relationship, primary caregiver status or any of the psychosocial measures. To establish the level of postoperative regret, participants were asked whether, hypothetically, they would choose to be a living kidney donor again. This translated into a rate of regret of 6.8% at 3 months and 10.7% at 12 months. It was not possible to establish predictors of regret due to small numbers. The majority of participants felt that they would continue to feel the same way about being a donor, regardless of what happened in the future. Again, there was no statistically significant correlation with regret and any of psychosocial measures.

Participants had received praise from others, and only a small proportion felt that receiving praise was important. Many felt that their self-esteem had increased; however, there was no correlation between participants' perceptions of self-esteem and answers given to the Rosenberg Self-esteem Questionnaire. Many also felt that the process had changed their outlook on life and this correlated positively with 3-month wellbeing ($n = 80$, $r = 0.258$, $P = 0.023$), self-esteem ($n = 75$, $r = 0.232$, $P = 0.045$) and social comparison scores ($n = 79$, $r = 0.316$, $P = 0.005$).

## Discussion

The aim of this study was to determine whether it was possible to quantify the psychological impact of LKD through the utilization of well-established psychosocial outcome measures. This was in an attempt to bridge the gap between the qualitative and quantitative literature by conducting a thorough and comprehensive prospective assessment of living donors.

This study has demonstrated no change in wellbeing over the first year after living kidney donation. Of the eleven validated measures used, none changed significantly over time. In contrast to these findings were the results of the new LKD questions which demonstrated that the majority of donors felt very positively about donation. We are therefore left with contradictory outcomes; that is, the benefit experienced as a result of LKD does not appear to translate into improvements in psychosocial questionnaire scores.

Due to the methodological issues identified within the review by Clemens et al. [12], the results from previously conducted studies are mixed. With regard to postoperative mood and anxiety, there are only a handful of studies that have measured these prospectively [15,17,22,23,29–32]. Our study is in keeping with two of these [15,17], both of which sampled donors at similar time points. The assessment of HRQoL in this study was limited to the Physical Component Summary (PCS) score of the SF-12 and the findings are again in keeping with those reported elsewhere [14–18,20,21,33]. This study failed to demonstrate the 12-month return to baseline that has been documented previously; however, our participants' 12-month PCS scores were not found to be statistically significantly different to their preoperative baseline.

Prior to this study, self-esteem in living kidney donors had been measured prospectively in three studies [15,34,35]. Only one used a validated measure [34] and showed that self-esteem increased in 51% of donors, stayed the same in 21% and decreased in 28% when measured 5-8 years after donation. Our study is the first to report data from the first postoperative year, and we demonstrated no significant change. The self-esteem scores obtained via the Rosenberg questionnaire provide the greatest contradiction against the LKD questions. The majority of participants stated that their self-esteem had increased; however, this did not translate into a change in Rosenberg scores. This was somewhat surprising as validation tests showed a medium–high correlation between the two scales. A possible explanation is that participants may have misinterpreted the positive emotions of having donated a kidney as an increase in self-esteem, or that a longer period of time is needed for the Rosenberg score to change significantly.

The remainder of the LKD questions showed that the majority of participants felt positively about LKD; however, again these were not associated with significant improvements in the psychosocial questionnaire scores. The rate of regret at both 3 and 12 months is in keeping with rates reported elsewhere (0–17%) [14,24,30,35–42]. Previously documented risk factors for regret, such as graft loss and complications, were not elicited from this study, most likely due to the small numbers of participants expressing evidence of regret and the small number of deaths and graft losses. The finding that participants whose recipients had suffered a complication were significantly lower in mood than those whose recipients had not suffered a complication is partially in keeping with other studies; however, these have additionally demonstrated an increase in donors' psychological symptoms with donor complications [43].

It is possible that the lack of change in psychosocial questionnaire scores over time represents social desirability when completing the questionnaires or a lack of sensitivity in generic psychosocial measures when attempting to capture data on living donor outcomes.

**Table 4.** Comorbidities, surgical and mental health history and preoperative physical data.

| Variable | Statistic (*n* = 100) |
|---|---|
| Comorbidities | |
| Yes | 46 |
| Past surgical history (procedure requiring general anaesthetic) | |
| Yes | 63 |
| Past or current mental health illness | |
| Yes | 27 |
| Received former treatment (therapy/medications) | 27 (100%) |
| Were seen by a psychologist/ psychiatrist preoperatively (as part of donor workup) | 20 (74.1%) |
| On antidepressants at the time of donation | 6 |
| No | 72 |
| Were seen by a psychologist/psychiatrist preoperatively (as part of donor workup) | 18 (25%) |
| Smoking status | |
| Current smoker | 13 |
| BMI | |
| Mean (SD) | 26.1 (3.95) |
| Preoperative blood results | |
| Creatinine (μmol/l) (mean, SD) | 82.8 (1.69) |
| eGFR (ml/min) (mean, SD) | 87.2 (15.9) |
| 12-month blood results | |
| Creatinine (μmol/l) (mean, SD) | 113.4 (22.167) |
| eGFR (ml/min) (mean, SD) | 55.8 (10.537) |

**Table 5.** Transplant details and recipient demographics.

| Variable | *n*/% |
|---|---|
| Type of donation | |
| Direct | 91 |
| Paired/pooled donation | 4 |
| Unspecified | 5 |
| Donor–recipient relationship | |
| Parents | 38 |
| Child (<18) | 19 |
| Child (>18) | 19 |
| Spouses | 21 |
| Siblings | 11 |
| Donated to a parent | 6 |
| Distant relatives | 13 |
| Friends | 6 |
| Unspecified | 5 |
| Mean recipient age at donation (years (SD)) | |
| Adults | 43.3 years (15.09) |
| Children | 7.6 years (5.0) |
| Dialysis type | |
| Pre-emptive | 33 |
| Haemodialysis | 48 |
| Peritoneal dialysis | 13 |
| N/A – unspecified | 5 |
| Years of dialysis | Mean 3.8 years (SD 3.15) |
| 1–3 years | 35 (57.3%) |
| 4–6 years | 16 (26.2%) |
| ≥7 years | 10 (16.4%) |
| Previous kidney transplant | |
| Yes | 23 |
| No | 70 |
| N/A – unspecified | 5 |
| Compatibility | |
| Incompatible transplant (blood group, tissue type) | 20 |

As mentioned in the introduction, the qualitative literature reiterates the complexities of living donation and how benefit is likely to comprise a number of different factors. The multiple contributors to donor benefit may well elude capture through validated measures, simply because these measures are insufficiently sensitive or capture only one of many components.

Another possible explanation for the lack of change in psychosocial questionnaire scores may be due to the narrow time frame over which the study was conducted. This study captured data over a 12- to 13-month period which is part of a much longer process. One may hypothesize that had the same questionnaires been administered earlier in the donation process, the scores may have been worse due to the potential distress associated with the workup process, the uncertainty of whether donation will proceed and the long-standing psychological impact of having a loved one with kidney disease. Comparatively, in the immediate preoperative period the donor can be more confident that the transplant will go ahead and this may be reflected in an improvement in questionnaire scores. Similarly, postoperative scores were obtained over the first year after donation, and it may be that the benefits of donation only start to become significant after the first 12 months, once the threat of rejection and other postoperative complications is reduced.

The next natural step in conducting further research would be to expand the data capture period to include donors from the moment they commence their workup, through to 5–10 years after donation. The additional advantage of doing this would be that one could also capture data from those who do not go on to donate. By comparing those that donate with those that do not donate, one would then be able to determine whether or not change in psychosocial questionnaire scores

**Table 6.** Correlation matrix of psychosocial variables (Pearson correlation).

| | Wellbeing | Distress | Mood | Stress | Physical HRQoL | Life satisfaction | Self-esteem | Anxiety | Social support | Optimism | Social comparison |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Wellbeing | | | | | | | | | | | |
| Correlation | 1.000 | −0.479 | −0.395 | −0.394 | 0.211* | 0.530† | 0.359† | −0.542 | 0.145 | 0.288† | 0.131 |
| Sig. (two-tailed) | | 0.000 | 0.000 | 0.000 | 0.036 | 0.000 | 0.000 | 0.000 | 0.154 | 0.004 | 0.203 |
| *N* | 100 | 94 | 100 | 99 | 99 | 100 | 98 | 96 | 98 | 97 | 97 |
| Distress | | | | | | | | | | | |
| Correlation | −0.479 | 1.000 | 0.633† | 0.596† | −0.282 | −0.391 | −0.506 | 0.627† | −0.090 | −0.333 | −0.278 |
| Sig. (two-tailed) | 0.000 | | 0.000 | 0.000 | 0.006 | 0.000 | 0.000 | 0.000 | 0.392 | 0.001 | 0.008 |
| *N* | 94 | 94 | 94 | 93 | 93 | 94 | 92 | 90 | 92 | 91 | 91 |
| Mood | | | | | | | | | | | |
| Correlation | −0.395 | 0.633† | 1.000 | 0.430† | −0.395 | −0.416 | −0.366 | 0.517† | −0.084 | −0.354 | −0.261 |
| Sig. (two-tailed) | 0.000 | 0.000 | | 0.000 | 0.000 | 0.000 | 0.000 | 0.000 | 0.412 | 0.000 | 0.010 |
| *N* | 100 | 94 | 100 | 99 | 99 | 100 | 98 | 96 | 98 | 97 | 97 |
| Stress | | | | | | | | | | | |
| Correlation | −0.394 | 0.596† | 0.430† | 1.000 | −0.404 | −0.437 | −0.050 | 0.441† | −0.076 | −0.503 | −0.294 |
| Sig. (two-tailed) | 0.000 | 0.000 | 0.000 | | 0.000 | 0.000 | 0.000 | 0.000 | 0.458 | 0.000 | 0.004 |
| *N* | 99 | 93 | 99 | 99 | 99 | 99 | 97 | 95 | 97 | 96 | 96 |
| Physical HRQoL | | | | | | | | | | | |
| Correlation | 0.211* | −0.282 | −0.395 | −0.404 | 1.000 | 0.272† | 0.333† | −0.176 | 0.241* | 0.229* | 0.242* |
| Sig. (two-tailed) | 0.036 | 0.006 | 0.000 | 0.000 | | 0.007 | 0.001 | 0.088 | 0.017 | 0.025 | 0.018 |
| *N* | 99 | 93 | 99 | 99 | 99 | 99 | 97 | 95 | 97 | 96 | 96 |
| Life satisfaction | | | | | | | | | | | |
| Correlation | 0.530† | −0.391 | −0.416 | −0.437 | 0.272† | 1.000 | 0.407† | −0.468 | 0.268† | 0.530† | 0.202* |
| Sig. (two-tailed) | 0.000 | 0.000 | 0.000 | 0.000 | 0.007 | | 0.000 | 0.000 | 0.008 | 0.000 | 0.047 |
| *N* | 100 | 94 | 100 | 99 | 99 | 100 | 98 | 96 | 98 | 97 | 97 |
| Self-esteem | | | | | | | | | | | |
| Correlation | 0.359† | −0.506 | −0.366 | −0.496 | 0.333† | 0.407† | 1.000 | −0.322 | 0.307† | 0.422† | 0.461† |
| Sig. (two-tailed) | 0.000 | 0.000 | 0.000 | 0.000 | 0.001 | 0.000 | | 0.002 | 0.002 | 0.000 | 0.000 |
| *N* | 98 | 92 | 98 | 97 | 97 | 98 | 98 | 94 | 97 | 96 | 95 |
| Anxiety | | | | | | | | | | | |
| Correlation | −0.542 | 0.627† | 0.517† | 0.441† | −0.176 | −0.468 | −0.322 | 1.000 | −0.152 | −0.451 | −0.104 |
| Sig. (two-tailed) | 0.000 | 0.000 | 0.000 | 0.000 | 0.088 | 0.000 | 0.002 | | 0.143 | 0.000 | 0.317 |
| *N* | 96 | 90 | 96 | 95 | 95 | 96 | 94 | 96 | 94 | 93 | 94 |
| Social support | | | | | | | | | | | |
| Correlation | 0.145 | −0.090 | −0.084 | −0.076 | 0.241* | 0.268† | 0.307† | −0.152 | 1.000 | 0.391† | 0.355† |
| Sig. (2-tailed) | 0.154 | 0.392 | 0.412 | 0.458 | 0.017 | 0.008 | 0.002 | 0.143 | | 0.000 | 0.000 |
| *N* | 98 | 92 | 98 | 97 | 97 | 98 | 97 | 94 | 98 | 96 | 95 |
| Optimism | | | | | | | | | | | |
| Correlation | 0.288† | −0.333 | −0.354 | −0.503 | 0.229* | 0.530† | 0.422† | −0.451 | 0.391† | 1.000 | 0.458† |
| Sig. (two-tailed) | 0.004 | 0.001 | 0.000 | 0.000 | 0.025 | 0.000 | 0.000 | 0.000 | 0.000 | | 0.000 |

**Table 6.** Continued.

| | Wellbeing | Distress | Mood | Stress | Physical HRQoL | Life satisfaction | Self-esteem | Anxiety | Social support | Optimism | Social comparison |
|---|---|---|---|---|---|---|---|---|---|---|---|
| *N* | 97 | 91 | 97 | 96 | 96 | 97 | 96 | 93 | 96 | 97 | 94 |
| Social comparison | | | | | | | | | | | |
| Correlation | 0.131 | −0.278 | −0.261 | −0.294 | 0.242* | 0.202* | 0.461† | −0.104 | 0.355† | 0.458† | 1.000 |
| Sig. (two-tailed) | 0.203 | 0.008 | 0.010 | 0.004 | 0.018 | 0.047 | 0.000 | 0.317 | 0.000 | 0.000 | |
| *N* | 97 | 91 | 97 | 96 | 96 | 97 | 95 | 94 | 95 | 94 | 97 |

*Correlation is significant at the 0.05 level (two-tailed).

†Correlation is significant at the 0.01 level (two-tailed).

**Table 7.** Estimated means for the psychosocial questionnaires at each time point (preoperatively, and 3 months and 12 months postoperatively).

| | Preoperatively | | | | 3 months | | | | 12 months | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Validated measures | *n* | Mean | SE | 95% CI | *n* | Mean | SE | 95% CI | *n* | Mean | SE | 95% CI |
| Wellbeing | 100 | 29.5 | 0.56 | 28.4, 30.6 | 79 | 29.5 | 0.61 | 28.3, 30.7 | 76 | 29.7 | 0.74 | 28.2, 31.1 |
| Distress | 94 | 10.3 | 0.46 | 9.3, 11.2 | 77 | 9.2 | 0.54 | 8.2, 10.3 | 74 | 10.6 | 0.58 | 9.4, 11.7 |
| Mood | 100 | 0.54 | 0.01 | 0.36, 0.72 | 81 | 0.62 | 0.11 | 0.39, 0.85 | 76 | 0.85 | 0.15 | 0.56, 1.1 |
| Stress | 99 | 4.5 | 0.27 | 3.9, 5.0 | 81 | 4.4 | 0.33 | 3.7, 5.0 | 76 | 5.0 | 0.34 | 4.4, 5.7 |
| SF-12 (physical) | 99 | 28.4 | 0.25 | 27.9, 28.9 | 79 | 25.2 | 0.54 | 24.1, 26.3 | 74 | 27.6 | 0.38 | 26.8, 28.3 |
| Life satisfaction | 100 | 25.2 | 0.64 | 23.9, 26.5 | 82 | 24.1 | 0.79 | 22.6, 25.7 | 77 | 24.3 | 0.76 | 22.8, 25.8 |
| Self-esteem | 98 | 22.6 | 0.50 | 21.6, 23.5 | 77 | 22.1 | 0.53 | 21.0, 23.1 | 76 | 22.1 | 0.50 | 21.1, 23.1 |
| Anxiety | 96 | 10.7 | 0.40 | 9.9, 11.5 | 78 | 10.3 | 0.43 | 9.5, 11.1 | 73 | 10.7 | 0.50 | 9.8, 11.6 |
| Social support | 98 | 70.0 | 1.3 | 66.4, 71.6 | 78 | 66.5 | 1.6 | 63.3, 69.6 | 77 | 65.7 | 1.3 | 63.2, 68.2 |
| Optimism | 97 | 21.1 | 0.58 | 20.0, 22.3 | 80 | 20.9 | 0.62 | 19.6, 22.1 | 73 | 20.6 | 0.65 | 19.3, 21.9 |
| Social comparison | 97 | 68.7 | 1.6 | 65.5, 71.9 | 81 | 67.8 | 1.6 | 64.7, 70.9 | 75 | 67.6 | 1.5 | 64.7, 70.5 |

Linear mixed models; CI, confidence intervals; SE, standard error.

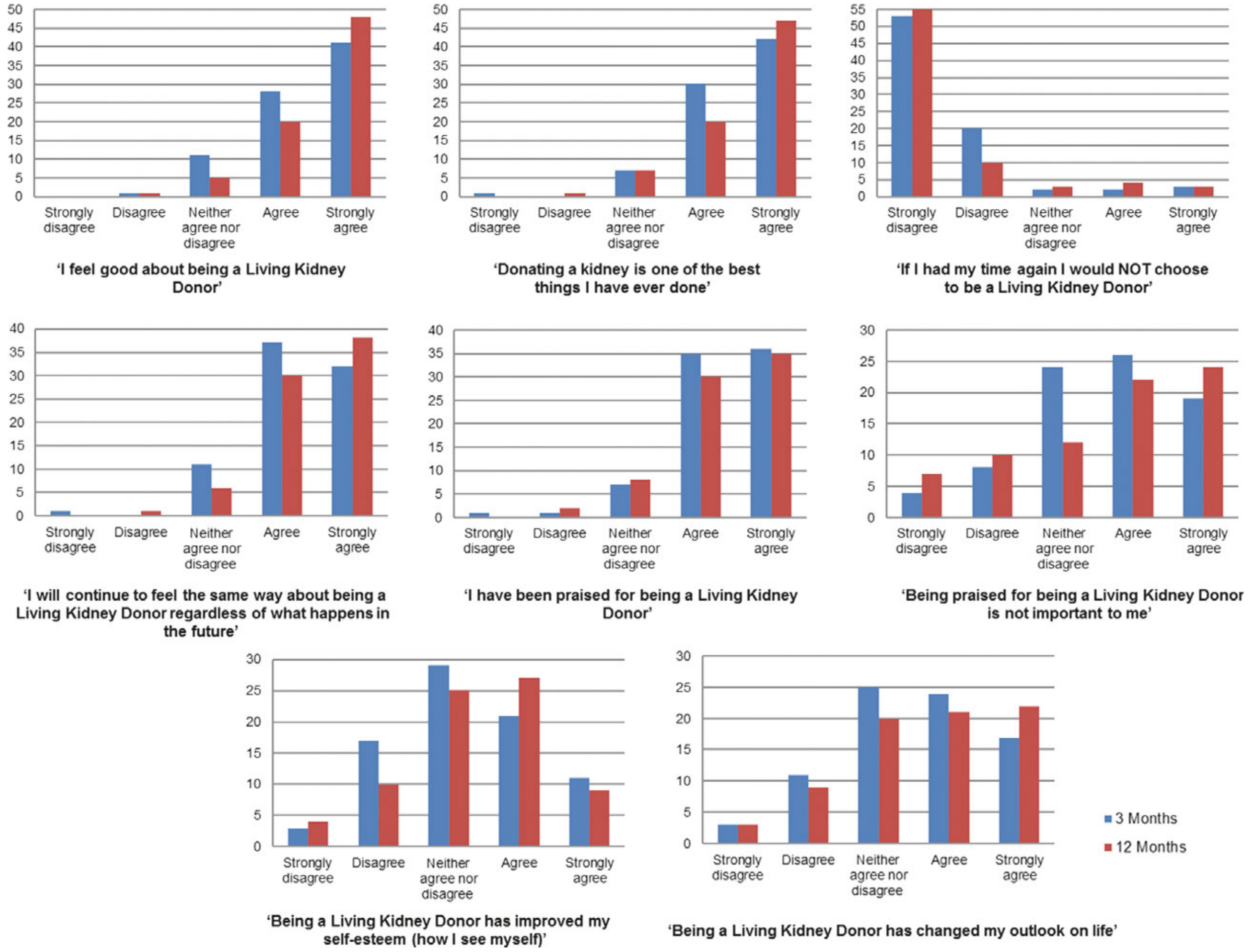
conveys a relative psychosocial benefit when compared to not donating at all, where scores may continue to decline.

## Strengths

This study contributes significantly to the literature by virtue of its prospective design, relatively large sample size and the range of different psychosocial factors measured. It has included the broadest range of validated measures to date and is the first to use validated questionnaires to prospectively measure stress, social support and social comparison in living donors. Attempts to measure stress and social factors previously have only utilized self-designed questions and have focussed predominantly on donor–recipient relationships [21,22,34,35]. The use of questions specific to LKD, which underwent validation prior to inclusion, adds to the richness of the data obtained and reiterates that donors feel very positively towards donation. Finally, this study also had a good retention rate and a thorough assessment was made to attempt detection of reasons why participants were lost to follow-up.

## Limitations

The limitations of this study may include the before-mentioned narrow time period over which data were collected. Additionally, a control group was also not used and this was because we were unable to identify a patient group that would act as a suitable control. Review of the literature demonstrates that living donors have been compared with a range of different patient groups, and consequentially, it is very difficult to compare studies with one another. There is also no consensus on what the best control group would be. Comparing living donors to national data from population surveys may underestimate the psychosocial morbidity attributable to living donation. This is principally because the questionnaire scores are likely to be lower



'I feel good about being a Living Kidney Donor'

'Donating a kidney is one of the best things I have ever done'

'If I had my time again I would NOT choose to be a Living Kidney Donor'

'I will continue to feel the same way about being a Living Kidney Donor regardless of what happens in the future'

'I have been praised for being a Living Kidney Donor'

'Being praised for being a Living Kidney Donor is not important to me'

'Being a Living Kidney Donor has improved my self-esteem (how I see myself)'

'Being a Living Kidney Donor has changed my outlook on life'

**Figure 2** Questions specific to donation and transplantation.

in a population survey due to the inclusion of individuals who are affected by both acute and chronic illness [17]. By claiming that living donors are on a par with this group postoperatively, when they are likely to have been significantly better preoperatively, it may artificially reassure the reader that living donation has no negative effect [13]. Clemens and colleagues suggest the use of potential donors who are medically and psychologically fit, but who do not donate for other reasons. Although this group may be a more closely matched control in terms of baseline characteristics and physical health, one must not underestimate the potential psychosocial implications of not being able to donate, especially if these individuals were the only potential donor for their recipient [44]. An additional limitation is that whilst a range of psychosocial measures were used, not all aspects of mental health (such as obsessive–compulsive symptoms and psychoticism) are measured.

### Implications for clinical practice

Transplant clinicians may use the data presented in this study to inform future donors regarding the anticipated psychological outcomes after donation. This study has shown that donors feel positively about LKD; however, this is not objectively demonstrable through an improvement in psychosocial questionnaire scores. Additionally, this study provides reassurance that current clinical guidelines are effective, with preservation of good psychological and physical health postoperatively.

## Conclusions

This study provides a thorough assessment of psychosocial outcomes in living kidney donors over the first year after living donation. It has demonstrated that although donors feel positively about LKD, this does not translate into a demonstrable improvement in validated psychosocial questionnaire scores. Whilst there was no improvement in psychosocial questionnaire scores to demonstrate benefit, there was also no evidence of harm.

## Authorship

HM: participated in research design, performance of the research, data analysis and writing of the manuscript. JC: participated in research design, data analysis and writing of the manuscript. JW: participated in research design and editing of the manuscript. NM: participated in research design and writing and editing of the manuscript.

## Funding

Project grant from the Guy’s and St Thomas’ Hospital Charity.

## Conflict of interest

The authors declare no conflict of interests.

## Acknowledgements

This research was funded by the Guy’s and St Thomas’ Charity and was supported by the National Institute for Health Research (NIHR) Biomedical Research Centre at Guy’s and St Thomas’ NHS Foundation Trust and King’s College London. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

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