

## ORIGINAL ARTICLE

# Development and validation of a questionnaire to assess fear of kidney failure following living donation

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## Introduction

In the United States, more than 5000 adults annually undergo voluntary donor nephrectomy for the expressed benefit of improving the quality of life of others with chronic renal insufficiency [1]. Research has shown that subsequent renal failure, incidence of kidney transplantation, and overall life expectancy in living kidney donors (LKDs) do not differ systematically from that of the nondonor general population [2–5]. In addition to being informed about the relative risks of surgery and possible short-term complications [6], carefully selected healthy

## Summary

Living kidney donors (LKDs) may feel more anxious about kidney failure now that they have only one kidney and the security of a second kidney is gone. The aim of this cross-sectional study was to develop and empirically validate a self-report scale for assessing fear of kidney failure in former LKDs. Participants were 364 former LKDs within the past 10 years at five US transplant centers and 219 healthy nondonor controls recruited through Mechanical Turk who completed several questionnaires. Analyses revealed a unidimensional factor structure, excellent internal consistency ( $\alpha = 0.88$ ), and good convergent validity for the Fear of Kidney Failure questionnaire. Only 13% of former donors reported moderate to high fear of kidney failure. Nonwhite race (OR = 2.9,  $P = 0.01$ ), genetic relationship with the recipient (OR = 2.46,  $P = 0.04$ ), and low satisfaction with the donation experience (OR = 0.49,  $P = 0.002$ ) were significant predictors of higher fear of kidney failure. We conclude that while mild anxiety about kidney failure is common, high anxiety about future renal failure among former LKDs is uncommon. The Fear of Kidney Failure questionnaire is reliable, valid, and easy to use in the clinical setting.

adults are generally told by transplant programs that they are at low risk of developing future kidney disease and can expect to live a normal life in the years following donation [5]. With relatively few exceptions, the long-term health-related quality of life of LKDs is excellent [7–9].

Despite the favorable long-term outcomes, researchers have found that some LKDs experience psychological stress, including anxiety, following donation [10–12]. Anxiety in LKDs may be secondary to the recipient's poor health status, graft failure, perceived changes in the donor's relationship with the recipient, and secondary stressors precipitated by donation (e.g., missed work, financial strain). One

additional source of anxiety for former LKDs may be fear of kidney failure. Despite reassurances from the transplant community about the favorable long-term outcomes associated with living donation, some LKDs nevertheless may feel more anxious about kidney failure now that they have only one kidney and the security of a second kidney is gone. It is conceivable that such fear or anxiety about future kidney failure may adversely affect otherwise favorable psychological outcomes for former LKDs. Notwithstanding the obvious differences between the two populations, research has consistently shown that fear of cancer recurrence among adults successfully treated across many cancer types is highly prevalent and strongly associated with worse psychological outcomes [13–16].

To date, there has been no effort to examine fear of kidney failure in former LKDs. Therefore, the primary purpose of this study was to develop and evaluate a brief instrument to assess anxiety or fear of future kidney failure in this population. Secondary aims of the study were to assess the prevalence of fear of kidney failure in a cohort of former donors and to examine its association with donor sociodemographic characteristics. We hypothesized a low prevalence rate (<20%) of fear of kidney failure and that genetically related donors would report higher fear of kidney failure than unrelated donors because they are related to someone with a history of kidney disease.

## Methods

All study procedures were approved initially by the Committee on Clinical Investigations at Beth Israel Deaconess Medical Center, Protocol #2011P-000359) and then subsequently by the Institutional Review Boards of each participating institution.

### Development of Fear of Kidney Failure (FKF) questionnaire

To generate items for the FKF questionnaire, we (i) reviewed publications describing the anxieties, worries, or concerns about future kidney functioning reported by former donors, (ii) solicited input from three nephrologists, two surgeons, three nurse coordinators, and two social workers with experience in the evaluation and care of LKDs, and (iii) sought guidance from three former LKDs. Collectively, these sources generated nine items, which had overlapping content or themes that were combined into five items. Instructions were developed, asking the respondent to indicate how fearful they are about each item, using the following response options – “not at all fearful” (scored 1), “somewhat fearful” (scored 2), “moderately fearful” (scored 3), “very fearful” (scored 4), and “extremely fearful” (scored 5). Higher scores indicate more fear or anxiety

about future kidney-related health. Four former LKDs completed the 5-item measure and provided us with feedback about wording, which led to minor editing and the final version of the measure used with LKDs in the present study (Table 1). For the nondonor controls (NDCs), the item wording was adjusted slightly to remove reference to kidney donation.

### Living kidney donors (LKDs)

Adults who donated a kidney in the past 10 years at five transplant centers in the United States (Beth Israel Deaconess Medical Center in Boston, MA, USA; Maine Medical Center in Portland, ME, USA; Montefiore Medical Center in Bronx, NY, USA; Vanderbilt University Medical Center, Nashville, TN, USA; and Medical University of South Carolina, Charleston, SC, USA) were mailed a description of the study purpose, a questionnaire packet, and a prepaid return envelope. We chose to focus only on those who donated within the past 10 years, as contact information for former LKDs was most reliable within this timeframe. Reasons for not participating in the study were not collected.

In addition to the FKF questionnaire, LKDs completed three other validated questionnaires: (i) SF-36 Health Survey [17] – measures perceived health status and is comprised of eight subscales and two composite scores – Physical Component Summary (PCS) and Mental Component Summary (MCS). Subscale and component scores are standardized to the general population with a mean score of 50 and a standard deviation of 10, with higher scores reflecting better perceived health status. (ii) Life Orientation Test-Revised (LOT-R) [18] – comprises items reflecting an optimistic (three items; e.g., “In uncertain times, I usually expect the best.”) or pessimistic (three items; e.g., “I rarely count on good things happening to me.”) outlook. A total score is calculated by summing the optimism and the inverted pessimism item scores (range: 0–24, higher scores reflect more optimism). (iii) Brief Symptom Inventory (BSI) short form [19] – asks respondents to indicate the degree to which they are distressed by certain depression, anxiety, and somatization symptoms, with higher scores reflecting more symptom disturbance. They were also asked to indicate their overall satisfaction with the donation experience (1 = not at all satisfied to 5 = extremely satisfied) and whether they had any regret about the donation decision.

### Nondonor controls (NDCs)

A healthy comparison group was recruited through Mechanical Turk ([www.mTurk.com](http://www.mTurk.com)), an online crowdsourcing worksite developed by Amazon in 2005. Requesters post Human Intelligence Tasks (HITs) on the website,

**Table 1.** Fear of Kidney Failure questionnaire.

Questionnaire items	Response options				
	Not at all fearful	Somewhat fearful	Moderately fearful	Very fearful	Extremely fearful
"How fearful are you about..."					
	▼	▼	▼	▼	▼
Medical or surgical complications from kidney donation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My remaining kidney failing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
An injury to my remaining kidney	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My lifestyle and how that might affect my remaining kidney	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Needing a kidney transplant in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

and registered "workers" can choose to complete the task (e.g., surveys) for a nominal fee. Requesters can set parameters or filters to limit participation to prescribed study qualifications. For the present study, we limited participation to adults older than 18 years, residing in the United States, with no chronic health problems, no family history of chronic kidney disease, and no history of living kidney donation. Also, we over-sampled for females and adults over age 45, considering that living donation is more common among women and middle-aged adults [1]. Numerous researchers have demonstrated that mTurk is a reliable and valid approach to obtaining survey data from a demographically diverse sample, with results comparable to those obtained using more traditional paper-and-pencil methods [20–22]. NDCs completed only the FKF questionnaire and a measure of social desirability [23]. Those with high levels of social desirability bias were excluded from the analysis.

### Statistical analyses

Data were analyzed using the PASW Statistics software (version 17.0; SPSS, Inc., Chicago, IL, USA). First, we calculated descriptive statistics on all demographic characteristics for the LKDs and NDCs, and used Fisher exact tests or t-tests to determine whether the two groups differed significantly on any variables. Second, exploratory factor analysis was performed to examine for dimensionality of the FKF questionnaire. A principal factors method was used to fit the common factor model. Third, Cronbach's alpha was calculated for the FKF questionnaire to assess internal consistency. Fourth, to examine for convergent validity, we computed Pearson correlation coefficients between FKF total score and scores on the physical health status, disposition optimism, and psychological symptom measures. Convergent validity reflects the degree to which scores on the FKF questionnaire correlate with other measures that are conceptually or theoretically related. We hypothesized that higher FKF total scores would be moderately correlated with higher anxiety and somatization (BSI), less optimism

(LOT-R), and lower perceived physical health status (SF-36 PCS). Fifth, we used t-tests to compare item and total scores on the FKF questionnaire between LKDs and NDCs. Finally, based on FKF questionnaire scores, we grouped LKDs into those with no/low (score  $\leq 10$ ) versus moderate/high fear (score  $>10$ ) of future kidney-related health problems. We then conducted univariate analyses (*t*-test or Fisher exact test) to examine whether these two groups differed on demographic characteristics, and logistic regression analysis to identify multivariate predictors of higher fear of kidney failure.

## Results

### Participant characteristics

Three hundred and sixty-four LKDs across the five transplant centers returned usable questionnaires, which represented a participation rate of about 36% (of those donors who we were able to reach by mail). Mean age was 50.2 ( $\pm 11.3$ ) years, and median time since donation was 71 months. The majority was female (67%), white (81%) (7% black, 5% Hispanic, 2% Asian, 1% more than one race, 4% no response), married (60%), had initiated or completed college education (75%), and employed (68%) or retired (9%). Nearly half (48%) were related to the transplant recipient (13% spouses, 15% unrelated/directed, 9% nondirected, 15% no response), most (78%) reported being "very" or "extremely" satisfied with the donation experience overall, and the majority (81%) indicated they would make the same decision to be a donor (1% no, 2% unsure, 15% no response). LKD study participants did not differ systematically from the general LKD population in the United States from 2003 to 2012, with the exception of fewer minority donors in the study (19% vs. 30%,  $P < 0.001$ ).

Two hundred and forty-five NDCs responded to the mTurk survey posting. Twenty-six (11%) were excluded based on high scores on the social desirability measure, leaving 219 NDCs in the final sample. NDCs had a mean age of 38.7 ( $\pm 12.8$ ) years, and the majority was female

(69%), white (81%), not married (54%), college educated (84%), and employed (69%).

### Psychometric analysis of FKF questionnaire

#### Factor analysis

Using principal components analysis for LKDs, the Kaiser–Meyer–Olkin measure of sampling adequacy was acceptable (0.86) and the Bartlett’s sphericity test was significant ( $\chi^2 = 919$ ,  $P < 0.001$  for LKDs), suggesting distribution of FKF data met criteria for exploratory factor analysis. The scree test of eigenvalues suggested a one-factor solution was most parsimonious for both samples. All items had component loadings  $>0.50$  on the one factor and were retained. The factor accounted for 68.2% of the total item variance.

#### Reliability

A total FKF score was calculated by summing the five items, with scores ranging from 5 to 25. High internal consistency was found for the FKF questionnaire (Cronbach’s  $\alpha = 0.88$ ).

#### Validity

Correlational analyses showed significant associations (in the predicted direction) between higher FKF scores and BSI anxiety ( $r = 0.14$ ,  $P = 0.03$ ), BSI somatization ( $r = 0.24$ ,  $P < 0.001$ ), less optimism ( $r = -0.17$ ,  $P = 0.003$ ), and lower perceived physical health status ( $r = -0.23$ ,  $P < 0.001$ ). While statistically significant, these values are not particularly high and suggest that fear of kidney failure is related to, but distinct from, negative affect and perceived health status measures.

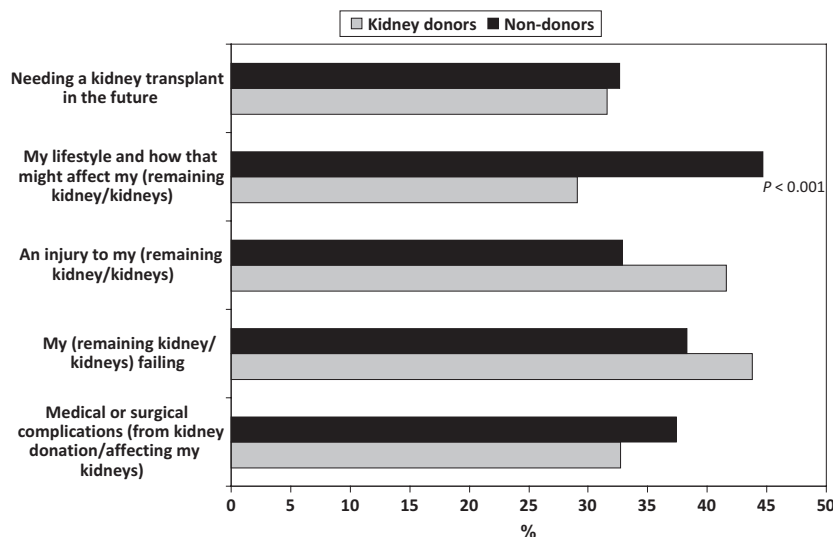
### Comparison of LDKs and NDCs

Living kidney donors and NDCs did not differ significantly on the FKF questionnaire mean total score ( $7.6 \pm 3.4$  vs.  $8.0 \pm 4.1$ ,  $t = 1.3$ ,  $P = 0.20$ ). Item analysis showed that NDCs were more likely than LKDs to report any fear of how their lifestyle may affect future kidney health ( $P = 0.01$ ) (Fig. 1).

### Variables associated with fear of kidney failure in LKDs

Living kidney donors were classified into two groups: those with no or low (FKF score  $\leq 10$ ,  $n = 317$ , 87%) and those with moderate or high (FKF score  $> 10$ ,  $n = 47$ , 13%) fear of future kidney-related health problems. Those with moderate/high fear were more likely to be genetically related to the recipient (20% vs. 8%,  $P = 0.001$ ), minority (29% vs. 10%,  $P = 0.001$ ), have lower perceived physical health scores ( $51.5 \pm 9.4$  vs.  $54.3 \pm 6.5$ ,  $t = 2.8$ ,  $P = 0.006$ ), have more regret about their donation decision (13% vs. 2%,  $P < 0.001$ ), and be less satisfied with the donation experience overall ( $3.9 \pm 1.0$  vs.  $4.6 \pm 0.7$ ,  $t = 5.7$ ,  $P < 0.001$ ).

Variables found to be significantly associated with fear of kidney failure in the univariate analyses were entered into the stepwise logistic regression analysis. Nonwhite race (OR = 2.9, 95% CI = 1.3, 6.7,  $P = 0.01$ ), genetic relationship with the recipient (OR = 2.46, 95% CI = 1.1, 5.7,  $P = 0.04$ ), and low satisfaction with the donation experience (OR = 0.49, 95% CI = 0.32, 0.77,  $P = 0.002$ ) were significant predictors of higher fear of kidney failure. The final multivariate prediction model ( $\chi = 40.4$ ,  $P < 0.001$ ) explained 23% of the variance in the outcome and correctly classified the outcome of 87% of patients.



**Figure 1** Percentage of living kidney donors and nondonor controls endorsing any concern (score  $>0$ ) on each Fear of Kidney Failure questionnaire item.

## Discussion

Overall, study findings support the reliability and validity of the FKF questionnaire in a sample of former LKDs. Factor analysis suggested that the instrument is unidimensional and all five items contributed sufficiently to the one factor. While associated with negative mood (e.g., anxiety, pessimism), analyses showed that fear of kidney failure is a distinct construct. Clinically, the FKF questionnaire can be administered easily and efficiently to former donors to assess whether they harbor any anxiety, worry, or fear about future kidney-related health problems. LKDs who have these concerns can be further assessed and counseled regarding the accuracy of their risk assessment, provided with information to recalibrate risk perception, and/or offered strategies to reduce renal injury or impairment if there is elevated risk.

It is reassuring that only a small percentage (13%) of LKDs report moderate or high fear of renal-related health problems. Indeed, the renal-related worry of LKDs is not greater than otherwise healthy nondonors. This finding may seem counterintuitive initially, but it is not entirely surprising. Prior to donation, LKDs undergo an extensive medical workup to ensure that they are in excellent physical health and have robust renal function. Following donation, LKDs are monitored medically at our respective centers or by their primary care physicians, which includes periodic assessments of renal function. Although having only one kidney may predispose some to excessive worry about future renal health, LKDs receive extensive feedback about kidney function and this likely serves to reassure them of excellent health generally and renal function specifically. Additionally, LKDs receive repeated messaging throughout the evaluation and follow-up phases of donation about the importance of maintaining a healthy lifestyle, which might explain why LKDs have less worry than NDCs about how their lifestyle might impact future kidney health.

Minorities and genetically related donors appear to be at highest risk of fear of kidney failure following donation. Perhaps the anxiety experienced by minorities, particular African-American donors, is not unfounded. African Americans, for instance, have a higher incidence of kidney disease [24], and some data suggest that they may be more likely than Whites to develop kidney failure or risk factors associated with future kidney failure after donation [25,26]. Despite repeated reassurances about their own excellent renal function following donation, some minority LKDs may still harbor some anxiety about their future risk of kidney-related health problems in light of higher risks in the minority population. Some acknowledge of this anxiety and a more culturally tailored discussion of risks of kidney-related health problems should be considered by providers during routine

postdonation follow-up appointments. Interestingly, we also found that genetically related LKDs were more likely to have moderate/high fears compared with those who were unrelated to the recipient. It is possible that they consider themselves to be at higher risk of kidney-related health problems due to their biologic association with the recipient who required transplantation. Additionally, having more exposure to someone with kidney disease may exacerbate worry or concern about developing a similar health problem in the future.

Notable strengths of the study are the involvement of multiple transplant centers, a large sample of LKDs, and the inclusion of a health nondonor comparison group. However, study findings should be evaluated within the context of several important limitations. While the LKDs in the study were representative of the general donor population in many ways, we had proportionally fewer minorities and this limits generalizability of the findings. Also, we did not assess some factors that may reasonably be expected to correlate with higher anxiety about future kidney-related problems in LKDs, including whether the donor's recipient lost their graft or whether the donor's kidney function has been routinely monitored. The response rate was relatively low and may be biased, such that those who did not respond may be more likely to have adverse outcomes and more fear of kidney failure. Finally, as this was a retrospective study, we were not able to assess the nature and course of fear of kidney failure in LKDs over time. Understanding longitudinal trends of such fear and anxiety is clinically important. For instance, LKDs with high fear of kidney failure that is maintained over time may suggest that the fear cannot easily be dismissed, which may precipitate emotional distress for some donors. Alternatively, if fear of kidney failure is short term and dissipates rather quickly, there may be little need for supportive interventions to address this issue. We are currently conducting a prospective study of the medical and psychosocial outcomes following LKD, which includes an assessment of fear of kidney failure.

In conclusion, only a small minority of former LKDs harbor anxiety about future kidney-related health problems. Moreover, such worry is less common among LKDs than healthy nondonors, perhaps due to routine surveillance of renal function. The field is in need of brief, validated measure to assess psychosocial outcomes in living donors. The FKF questionnaire appears to be a valid and reliable instrument for assessing, heretofore, an overlooked outcome among LKDs.

## Authorship

JR, DM: study design. JR, JV, BP, LK, SK: study oversight. JR, AF, TV, KG, DM: study implementation/data collection. JR, JW, JV, LK, PB, KC, SK, DM: data analysis/inter-

pretation. JR, TV, JW, JV, LK, PB, KC, SK, DM: manuscript preparation.

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