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The Spanish Version of the Fear of Kidney Failure Questionnaire: Validity, Reliability, and Characterization of Living Donors With the Highest Fear of Kidney Failure

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Background. Measures of fear of progression or recurrence of illnesses have been criticized for neglecting cross-cultural validity. Therefore, we assessed the psychometric properties of the Spanish version of the Fear of Kidney Failure Questionnaire (FKFQ), to determine whether postdonation fear of kidney failure (FKF) influenced the donors' psychosocial status, and define variables that characterized donors with high FKFQ scores. **Methods.** We included 492 participants (211 donors) in a multi-center, 11-year, retrospective, cross-sectional study. Donors were classified with a Latent Class Analysis of the FKFQ-item scores and characterized with a multivariable logistic regression analysis. We calculated the risk ratio based on predicted marginal probabilities. **Results.** The Spanish version of the FKFQ showed acceptable psychometric properties. FKF was uncommon among donors, but we detected a small subgroup (n=21, 9.9%) with high FKF (mean FKFQ score=14.5, 3.1 SD). Compared with other donors, these donors reported higher anxiety and depression (38% and 29% of potential anxiety and depressive disorders), worse quality of life, and less satisfaction with the donation. Donors with high FKFQ scores were characterized by higher neuroticism combined with postdonation physical symptoms that interfered with daily activities. **Conclusions.** The FKFQ was cross-culturally valid, and thus, it may be used to assess the FKF in Spanish-speaking donors. New interventions that promote positive affectivity and evidence-based treatments for worry could be adapted for treating FKF.

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INTRODUCTION

Transplantation from the selfless donation of a living kidney donor (LKD) is the best treatment for end-stage kidney disease. A living kidney donation reduces the transplantation delay and thus, reduces the risk of morbidity and deterioration in the recipient's growth and quality of life.[1]

Success with laparoscopic surgical techniques has favored an increase in living donations.[2] This increase, followed by the broadening of inclusion criteria for LKDs, might have increased the range of negative psychosocial outcomes such as psychological distress (eg, about 25% of LKDs report depression and anxiety disorders after donation,[3] and about 2% require sustained psychological treatment[4]), feeling that health worsened after donation thus decreasing quality of life, deterioration of the donor-recipient relationship, or economical burden due to donation.[5,6] Fear of failure in the remaining kidney (FKF) might be an overlooked adverse consequence in LKDs. The first studies assessing this fear with a single question indicated that it might affect 3%–36% of LKDs.[7-9] Another study in a US population validated the Fear of Kidney Failure Questionnaire (FKFQ). Results showed that 13% of LKDs feared losing their remaining kidney. These donors reported a worse quality of life, more dissatisfaction with the donation, and more regret concerning the donation.[10] In a prospective study, the same group found that 21% of LKDs developed a fear of kidney failure (FKF) after donation.[11]

Measures of fear of progression or recurrence of illnesses are mainly criticized when they neglect to assess cross-cultural validity.[12] It is unknown whether Spanish-speaking LKDs fear that their remaining kidney might fail. Ignorance of the true influence that the FKF might have in these donors might limit the information in informed consent procedures and prevent the early detection and treatment of that fear.

Therefore, the present study aimed to (a) linguistically validate a Spanish version of the FKFQ; (b) assess its validity, reliability, and factorial structure; (c) assess the influence of the FKF on LKD psychosocial status; and (d) define antecedents and psychosocial consequences that characterize LKDs with high FKFQ scores.

We hypothesized that (a) the psychometric properties of the Spanish FKFQ would be acceptable; (b) the proportion of LKDs with high FKF would be comparable to that observed in the original study; (c) LKDs with high FKF would show a worse health-related quality of life (HRQoL), higher anxiety and depression, less satisfaction with donation, and more regret concerning the donation; and (d) LKDs with high FKF would be characterized by high neuroticism, low extraversion and optimism, feelings of inadequate medical monitoring, and perceptions that the incidence of graft failure was high and the medical status was poor among recipients.

MATERIALS AND METHODS

This multicenter, retrospective, cross-sectional study included 6 Spanish Hospitals. The study was approved by the Ethics Committee of the Hospital Clinic of Barcelona (the coordinating center) and by the Institutional Ethics Committees at each participant center. The investigation was performed in accordance with the Declaration of Helsinki 2000. All LKDs provided written informed consent to participate.

Participants

We included a logistic regression analysis. Therefore, the sample size was calculated with Freeman's formula: $[n = 10*(k + 1)]$, where k is the number of independent variables.[13] Considering that a maximum of 20 variables could be introduced, the minimum sample size required was 210 cases.

Group of Living Kidney Donors

LKDs that donated in the participating centers from January 2005 through December 2015 were stratified by hospital and year of donation, then selected randomly. LKDs that met exclusion criteria or declined study participation were substituted from other potential participants (15%) that had been also stratified and randomly selected from the original pool. Our final sample included 211 LKDs.

Comparison Groups

Participants from the general population were recruited from university students (n = 172), who referred other participants from among their relatives and acquaintances.

We followed the recommendations of the original study to assess the specificity of the FKF.[10] We also included participants that hypothetically had an elevated perceived risk of kidney failure, including those genetically related to an individual with chronic kidney failure (CKF) (n = 80), recruited from relatives of transplant recipients other than the LKD and relatives of patients in hemodialysis, and those with a single kidney, due to cancer or trauma (n = 29).

Exclusion criteria were illiteracy or could not understand Spanish, kidney disease, or genetically related to an individual with a kidney disease other than CKF. Participants from the general population with a genetic relative with CKF were assigned to the proper comparison group (Figure 1).

Procedures
Recruitment

LKD demographic information was obtained from an ad hoc survey. All participants completed a paper survey delivered by postal mail or online through a personal, unrepeatable URL.

Linguistic Validation

Two independent translations of the FKFQ from English to Spanish were obtained from 2 professional translators that were native English speakers and bilingual in Spanish. The first 2 authors of this study and the translators agreed on a version conceptually equivalent to the original 1, which would be equally understandable in all Spanish dialects. The first version was back-translated by a professional English translator that was independent of the research team.[14] The final version of the FKFQ (SDC, English and Spanish versions of the FKFQ http://links.lww.com/TXD/A302) was tested in a pilot study with 20 LKDs, who confirmed the acceptability and comprehensibility of each item and, on average, completed the questionnaire in <3 minutes.

Variables and instruments
Fear of Kidney Failure Questionnaire

The FKFQ is a 5-item questionnaire that assesses worry or fear about future kidney-related health problems.[10] Response options ranged from "not at all fearful" (score = 1) to "extremely fearful" (score = 5). The FKFQ has been applied
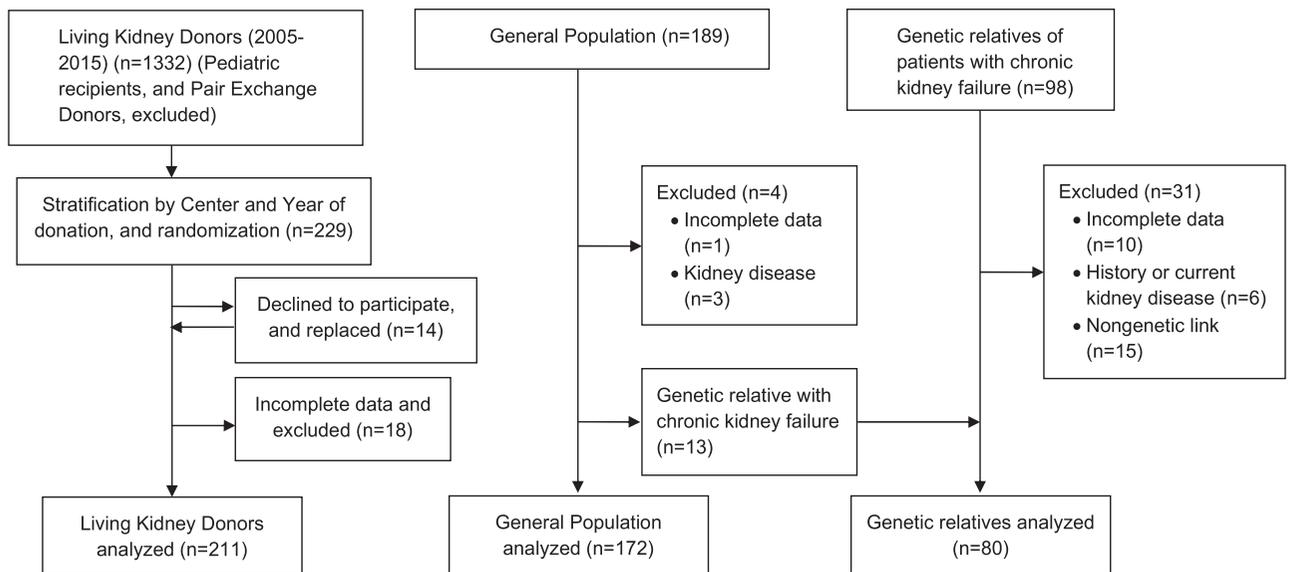
FIGURE 1. Flow diagram of participants.

to prospectively assess living donation outcomes in the United States. Results suggested that transplant programs and living donation websites inform potential LKDs about this possible negative outcome.[9]

Several psychological variables were expected to be related to the FKF. As measures of construct validity, we expected moderate correlations between the FKFQ and the following instruments, all of which had been validated in Spanish.

NEO Five-Factor Inventory-Revised

The NEO Five-Factor Inventory-Revised (NEO-FFI-R)[15] measures 5 personality dimensions: neuroticism (proneness to negative emotional states); extraversion (positive emotionality, assertiveness); agreeableness (empathy, altruism); conscientiousness (impulse control, according to social norms; discipline); and openness to experience (broad interests, need for variety). We expected positive correlations between neuroticism and the FKFQ, negative correlations with extraversion, and nonsignificant correlations between the other personality dimensions and the FKFQ.

Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) assesses symptoms of depression and anxiety.[16] It can be used to screen patients for potential anxiety and depressive disorders. The HADS does not include physical symptoms that might inflate the final scores. Hence, it seemed appropriate for assessing participants undergoing medical procedures.

We expected positive correlations between the HADS and the FKFQ. We expected a higher proportion of positive cases of anxiety and depressive disorders among LKDs with high FKFQ scores.

Life Orientation Test

The Life Orientation Test (LOT-R) measures optimism, which is a strong predictor of effective coping in stressful circumstances. The psychometric properties of the LOT-R validated in a Hispanic population[17] have been questioned.[18] Consequently, we decided to apply the Spanish version.[19,20]

We expected negative correlations between optimism and the FKFQ.

Short Form-36 Health Survey

The Short Form-36 Health Survey (SF-36) is a valid measure of HRQoL, in general and specific populations.[21] The weighted sum of its 8 subscales provides two 0–100 components: the physical health component (PCS_SP) (ie, interference with daily activities, pain, and fatigue) and the mental health component (ie, interference with emotional well-being). Higher scores reflected better HRQoLs.

We expected a worse HRQoL in LKDs with high FKFQ scores.

Satisfaction and Regrets Regarding the Kidney Donation

We used a 10-point visual analog scale (VAS) to measure the extents of satisfaction and regret, regarding the kidney donation, among LKDs. Higher scores expressed less satisfaction and more regret regarding the donation.

We expected less satisfaction and more regret regarding the donation in LKDs with high FKFQ scores.

Objective and Subjective Monitoring of Kidney Function

The original FKFQ validation found no differences between LKDs and the general population. This finding was attributed to the close medical monitoring of LKDs, which might have clarified doubts and thus dissipated fears.[10] However, that study did not assess the relationship between FKF and the actual frequency of medical monitoring. It is possible that FKFQ scores were higher in those LKDs undergoing less-frequent monitoring. Therefore, we assessed the number of medical visits arranged since donation, expressed both as the absolute number and as a proportion of the number of visits per year since the donation. We expected that closer LKD monitoring would result in lower FKFQ scores.

The feeling of proper monitoring might be independent of the actual degree of monitoring. This perception might influence the fear that the remaining kidney might be at risk. We

assessed the feeling of proper monitoring with a 10-point VAS. We expected higher VAS scores (ie, worse monitoring) in LKDs with high FKFQ scores.

Subjective Status of the Recipient

LKDs might feel that a negative outcome in their recipient might predict a similar course for the LKD. We measured LKD perceptions of their recipients' health with a 10-point VAS. We expected higher VAS scores (ie, a worse perceived outcome) in LKDs with high FKFQ scores.

Donor-recipient Relationship

In the original study, LKDs with high FKFQ scores were genetically related to their recipients more often than those with low FKFQ scores. LKDs might believe that genetics could increase their risk of kidney failure. Accordingly, we expected high FKFQ scores in donors that were genetically related to their recipients.

Statistical Methods

Data were analyzed with Stata Statistical Software: Release 16. All tests were 2-tailed. A 0.05 type I error was applied.

Internal Consistency, Reliability, and Factorial Structure

The internal consistency of the FKFQ was studied with Cronbach's alpha coefficient (α). Its factorial structure was studied with a principal component analysis.

In the 2–4 weeks after the first administration, the FKFQ was readministered to a random subgroup of LKDs, who reported no changes in health status. Temporal stability was assessed by calculating the intraclass correlation coefficient (ICC) between these 2 assessments.

Criterion Validity

Concurrent validity and divergent validity were assessed by calculating the correlations between the FKFQ and the NEO-FFI-R, HADS, and LOT-R.

Comparison Between the FKFQ Scores of LKDs and Control Groups

LKDs and control groups were compared in terms of demographics and FKFQ scores with ANOVA. In cases of significant skewness, we calculated the nonparametric Kruskal-Wallis test.

Characterization of LKDs With a High FKF and the Impact of a FKF on Psychosocial Status and Feelings About the Donation

The classification of LKDs based on FKFQ-item scores was assessed with a latent class analysis. Solutions from 1 to 3 classes were compared, based on Akaike and Bayesian information criteria (AIC and BIC, respectively).

Differences between classes were analyzed by comparing the mean and SD or the proportions. Variables with P values <0.20 in univariate analysis were assessed in a multivariable logistic regression model.[22] Considering that the stepwise method of selecting relevant variables was questioned,[23,24] we applied the best subset logistic regression strategy.[22] This method estimated all possible models with several predictors and ordered them according to a criterion, like the AIC. To facilitate interpretation, we calculated the risk ratio based on the predicted marginal probabilities.

RESULTS

Demographics and FKFQ Scores

The final sample comprised 492 participants. LKDs and participants with single kidneys were older than other participants. More LKDs were married or widowed than individuals in the general population comparison group (Table 1).

Raw comparisons and comparisons adjusted for gender and age showed that LKDs had the lowest FKFQ scores among the populations tested. Years since the donation did not influence the FKFQ score; it was nonsignificantly correlated with the FKFQ score (r = –0.10; P = 0.17). The median time since the donation was 8 years. The mean of the FKFQ scores above the median (6.89, 3.34 SD) was similar to the mean of the scores below the median (6.81, 2.96 SD).

Internal Consistency and Reliability

The internal consistency of the FKFQ was acceptable for the whole sample (α = 0.94, 95% CI, 0.93-0.95); for the LKDs (α = 0.90, 95% CI, 0.88-0.92); for the relatives (α = 0.94, 95% CI, 0.92-0.96); and for the general population (α = 0.93, 95% CI, 0.92-0.95). Principal factor analyses showed that a single factor could explain 82% of the total variance for the whole sample. Similar results were obtained for LKDs, the relatives, and the general population (72%, 82%, and 80%, respectively). Therefore, the FKFQ items appeared to be interdependent and homogeneous.

The ICC showed strong agreement between the FKFQ scores for questionnaires administered 2 weeks apart (ICC = 0.93, 95% CI, 0.84-0.97; P < 0.01). Accordingly, the temporal stability of the FKFQ was acceptable.

Criterion Validity

The FKFQ was positively correlated with neuroticism, anxiety, and depressive symptoms (Table 2). The FKFQ was unrelated to the dimensions that were unrelated to anxiety (ie, openness to experience, agreeableness, and conscientiousness). The FKFQ was essentially unrelated to the dimensions that predisposed to positive emotionality (extraversion and optimism).

Subgroups of LKDs, Divided According to the Fear of Kidney Failure

The best solution of the latent class analysis identified 3 subgroups of LKDs (AIC = 1407.99; BIC = 1481.73). Most LKDs (n = 143; 67.8%) reported the absence of a FKF (mean FKFQ = 5.2, 0.8 SD). The second group (n = 47; 22.3%) reported a moderate FKF (mean FKFQ = 8.2, 1.5 SD). Only 21 LKDs (9.9%) reported the highest FKF (mean FKFQ = 14.5, 3.1 SD).

No demographic differences were observed between LKD subgroups (Table 3). The proportions of genetic and nongenetic relationships with recipients were similar between LKD subgroups. The type of relationship with the recipient did not influence the FKFQ scores (genetic relationship = 6.84, 3.02 SD; nongenetic relationship = 6.96, 3.36 SD; F = 0.06; P = 0.81).

LKDs with the highest FKF showed high neuroticism, anxiety, and depression. A high percentage had potential anxiety and depressive disorders. These donors reported worse HRQoL and less satisfaction with the donation.

The risk model showed that LKDs with higher FKF were best characterized by high neuroticism and a low PCS_SP

TABLE 1.

Differences in sociodemographic characteristics between subsamples of participants

	LKDs (n = 211)	Relatives (n = 80)	Single kidney (n = 29)	General population (n = 172)	Chi-square/F value	d.f.	P
Gender, n (%)					19.88	3	<0.01
Female	131 (62%)	54 (67%)	7 (24%)	114 (66%)			
Male	80 (38%)	26 (33%)	22 (76%)	58 (34%)			
Age (y), mean (SD),	56.99 (10.14)	48.22 (15.23)	62.48 (11.51)	38.89 (16.32)	64.63	3	<0.01
Civil status, n (%)					67.95	3	<0.01
Single	24 (11%)	20 (25%)	6 (21%)	80 (46%)			
Married	155 (74%)	50 (63%)	20 (69%)	77 (45%)			
Divorced	17 (8%)	8 (10%)	1 (3%)	13 (8%)			
Widow	15 (7%)	2 (2%)	2 (7%)	2 (1%)			
Educational level, n (%)					57.73	3	<0.01
Elementary	75 (35%)	13 (16%)	11 (38%)	11 (6%)			
High school	73 (35%)	39 (49%)	12 (41%)	75 (44%)			
College	63 (30%)	28 (35%)	6 (21%)	86 (50%)			
FKFQ score, mean (SD)	6.81 (3.14)	9.06 (4.99)	11.34 (5.30)	12.45 (5.41)	123.95*	3	<0.01

*Kruskal-Wallis test.
FKFQ, Fear of Kidney Failure individuals with a single kidney; LKDs, living kidney donors; Single kidney, Questionnaire.

TABLE 2.

Pearson correlations between the Fear of Kidney Failure Questionnaire scores and variables related or unrelated to anxiety

	Fear of Kidney Failure Questionnaire				
	Whole sample (n = 492)	LKDs (n = 211)	Relatives (n = 80)	Single kidney (n = 29)	General population (n = 172)
NEO-FFI-R					
Neuroticism	**0.34**	**0.32**	**0.30**	0.19	**0.28**
Extraversion	0.05	0.03	0.26	−0.24	0.04
Openness to experience	0.04	0.05	0.13	0.16	−0.03
Agreeableness	**−0.14**	−0.02	−0.20	−0.03	−0.07
Conscientiousness	−0.08	0.00	−0.03	−0.14	−0.04
HADS					
Depression	**0.28**	**0.29**	0.22	**0.48**	0.15
Anxiety	**0.40**	**0.40**	0.25	**0.57**	**0.25**
LOT-R	**−0.12**	**−0.16**	**−0.24**	−0.22	−0.07

Bold indicates $P < 0.05$.
NEO-FFI-R, NEO Five-Factor Inventory-revised; individuals with a single kidney; LKD, living kidney donor; Single kidney, HADS, Hospital Anxiety and Depression Scale; LOT-R, Life Orientation Test (optimism).

(Hosmer-Lemeshow goodness of fit test: $P = 0.73$; area under the receiver-operating characteristic curve = 0.72). For every point of increase in neuroticism, the risk of belonging to the high FKF group increased by 1.08; and for every point of reduction (ie, worsening) in the PCS_SP, the risk increased by 1.02 (Table 4). Table 5 shows the risk of belonging to the highest FKF group, according to the degree of neuroticism combined with the PCS_SP. The combined maximum risk (86.6%) corresponded to LKDs with a T score of 75 in neuroticism and 25 in the PCS_SP.

DISCUSSION

The Spanish version of the FKFQ showed acceptable psychometric properties. The linguistic validation paid attention to the peculiarities in different Spanish dialects to prevent difficulties in comprehension. These findings suggested that the FKFQ is cross-culturally valid and could be used to assess the FKF in Spanish-speaking LKDs. From a clinical point of view, the Spanish FKFQ could identify postdonation concerns about future kidney problems in <3 minutes. Although high

FKFQ scores were uncommon among LKDs, early interventions could aim to reduce the high distress and worse HRQoL of those affected and prevent other negative outcomes, such as dissatisfaction with the donation or advice against living donations to others.

The moderate to low correlations between the FKFQ and anxiety and depression suggested that the FKF was a specific construct. However, high FKFQ scores might be an indication for a general psychological distress assessment, as suggested by the higher proportion of potential anxiety and depressive disorders among LKDs with higher FKFQ scores. We could not determine whether LKDs with high FKFQ scores were also anxious about health, in general. Those individuals might display maladaptive worrying, symptom checking, or adopting unnecessary precautions (eg, avoiding nonrisky activities). They might also neglect taking the necessary measures for reducing the risk of kidney loss (eg, by reducing attendance to follow-ups). Discovering new facets of the FKF might reveal a higher incidence and a greater impact compared with those observed to date.

As previously described,[25] we found that the FKF was mainly related to a proneness to negative affectivity

TABLE 3.

Comparison of sociodemographic and psychosocial characteristics between subgroups of LKDs

	LKD subgroups, grouped according to the FKFQ score			Chi-square/F value	d.f.	*P*
	AF (n = 143)	MF (n = 47)	HF (n = 21)			
Gender, n (%)				2.34	2	0.31
Female	84 (59%)	34 (72%)	13 (62%)			
Male	59 (41%)	13 (28%)	8 (38%)			
Age (y), mean (SD)	57.80 (10.15)	54.71 (10.64)	56.52 (8.49)	1.61	2	0.20
Civil status, n (%)				2.17	6	0.90
Single	16 (11%)	12 (25%)	4 (21%)			
Married	106 (74%)	29 (63%)	15 (69%)			
Divorced	11 (8%)	5 (10%)	1 (3%)			
Widow	10 (7%)	1 (2%)	1 (7%)			
Educational level, n (%)				3.21	4	0.52
Elementary	52 (36%)	13 (28%)	10 (47%)			
High school	47 (33%)	20 (42%)	6 (29%)			
College	44 (31%)	14 (30%)	5 (24%)			
Donor-recipient relationship, n (%) (n = 171)				0.30	2	0.86
Genetic	70 (61%)	24 (63%)	10 (56%)			
Emotional	45 (39%)	14 (37%)	8 (44%)			
HADS, mean (SD)						
Depression	1.38 (2.50)	1.57 (1.47)	3.19 (4.18)	4.65	2	0.01 (HF > MF = AF)
Anxiety	3.01 (2.79)	4.51 (2.71)	6.33 (5.18)	12.82	2	<0.001 (HF = MF > AF)
Potential cases of depressive disorder (HADS-D ≥ 5), n (%)	16 (11%)	2 (4%)	6 (29%)	8.73	2	0.01 (HF > MF = AF)
Potential cases of anxiety disorder (HADS-A ≥ 8), n (%)	10 (7%)	6 (13%)	8 (38%)	17.69	2	<0.001 (HF > MF = AF)
SF-36, mean (SD)						
Physical component	54.75 (5.33)	54.75 (4.04)	50.47 (8.41)	5.54	2	0.005 (HF < MF = AF)
Mental component	52.95 (8.20)	50.66 (7.50)	47.26 (13.02)	4.39	2	0.01 (HF = MF < AF)
NEO-FFI-R (T scores), mean (SD)						
Neuroticism	41.04 (8.08)	44.47 (7.03)	48.42 (9.00)	9.66	2	<0.001 (HF = MF < AF)
Extraversion	48.84 (7.24)	50.59 (8.06)	48.42 (7.01)	1.11	2	0.33
Openness to experience	49.11 (9.24)	48.86 (7.80)	49.08 (6.51)	1.12	2	0.98
Agreeableness	50.28 (7.88)	48.13 (7.90)	49.34 (7.06)	1.38	2	0.25
Conscientiousness	54.49 (8.14)	54.06 (7.38)	54.47 (7.04)	3.33	2	0.95
LOT-R (optimism), mean (SD)	16.24 (3.54)	15.39 (2.59)	14.95 (3.17)	2.12	2	0.12
Satisfaction with donation (0–10 VAS), mean (SD)	0.56 (1.52)	0.78 (1.72)	1.74 (3.12)	4.00	2	0.02 (HF > MF = AF)
Regretted the donation (0–10 VAS), mean (SD)	0.20 (0.41)	0.52 (1.52)	0.83 (2.30)	4.07	2	0.02
Graft function (recipient) (n = 195), n (%)				5.08	4	0.28
Optimal	116 (88%)	36 (84%)	15 (75%)			
Some problems	10 (8%)	2 (5%)	3 (15%)			
Graft failure	6 (5%)	5 (12%)	2 (10%)			
Subjective health status of the recipient (0–10 VAS), mean (SD)	1.11 (2.13)	1.33 (1.93)	1.39 (2.17)	0.28	2	0.76
Death of recipient, n (%)	7 (5%)	3 (6%)	1 (5%)	0.18	2	0.91
Medical monitoring of renal function (in LKD) (number of medical visits), mean (SD)	7.19 (4.32)	7.26 (3.75)	4.67 (2.87)	3.63	2	0.03 (HF < MF = AF)
Medical monitoring of renal function (in LKD) (number of medical visits per y), mean (SD)	1.35 (0.90)	1.51 (0.87)	1.23 (0.85)	0.70	2	0.50
Proper monitoring of renal function (in LKD) (0–10 VAS), mean (SD)	0.84 (1.98)	1.20 (1.64)	1.69 (2.48)	1.98	2	0.14
Subjective renal function (in LKD) (0–10 VAS), mean (SD)	0.50 (1.31)	0.69 (1.11)	1.14 (1.82)	2.27	2	0.11

AF, absence of fear; FKFQ, fear of kidney failure questionnaire; HADS, Hospital Anxiety and Depression Scale; HADS-D, Hospital Anxiety and Depression Scale-Depression Subscale; HADS-A, Hospital Anxiety and Depression Scale-Anxiety Subscale; HF, high fear; LKD, living kidney donor; LOT-R, life orientation test (optimism); MF, moderate fear; NEO-FFI-R, NEO Five-Factor Inventory-revised; VAS, visual analog scale.

(neuroticism). This personality dimension describes the system in charge of identifying and reacting to danger signals through the fear response. This finding might help explain why the majority of LKDs, who showed lower neuroticism than the general population,[25] also had the lowest FKFQ scores among the groups tested. Interventions developed

TABLE 4.

OR and RR predicted with a logistic model for differentiating LKDs with high vs nonhigh scores on the FKFQ

Test component	OR	95% CI OR	P	RR	95% CI RR	P
PCS_SP	0.93	0.87-1.00	0.06	0.98	0.96-1.01	0.18
T-N	1.08	1.01-1.14	0.02	1.08	1.01-1.14	0.02

FKFQ, Fear of Kidney Failure Questionnaire; PCS_SP, Physical Component of the Short Form-36 Health Survey (SF-36); RR, relative risk; T-N, T score in the Neuroticism dimension of the NEO Five-Factor Inventory (NEO-FFI-R); OR, odds ratio.

TABLE 5.

Risk of belonging to the group of living kidney donors with highest scores on the Fear of Kidney Failure Questionnaire, based on the combination of the neuroticism score and the physical component score on the SF-36

Physical component of the SF-36	Neuroticism (T score)					
	25	35	45	55	65	75
25	14.6	26.1	42.2	60.2	75.7	86.6
35	8.0	15.3	27.1	43.5	61.4	76.7
45	4.3	8.4	16.0	28.2	44.8	62.7
55	2.2	4.5	8.8	16.7	29.3	46.1
65	1.1	2.3	4.7	9.3	17.4	30.4
75	0.6	1.2	2.5	5.0	9.7	18.2

SF-36, Short Form-36 Health Survey.

to target the promotion of positive effects might be readily adaptable for treating the FKF.[26] Neuroticism also propends to overestimations and misidentifications of danger, and thus, it could lead to reactions of disproportionate fear. For example, the FKF might be disproportionate to a low risk of losing the remaining kidney.[27-29] This notion suggests that addressing high FKFQ scores with educative interventions might be insufficient. Alternative interventions, based on the available models of fear of recurrence, might be necessary.[30]

The most notable component of the FKF might be worry. Worry is a coping strategy for an anticipated threat (eg, kidney failure) that becomes pathological, when both positive beliefs (eg, worrying increases the preparedness to face uncertainty) and negative beliefs (eg, worrying is uncontrollable) are excessive.[31,32] Worry might be common to all types of fears of progression/recurrence related to health problems.[31,33] Psychological treatments can effectively improve uncertainty management and treat worry, regardless of the source.[34-36]

Persistent physical symptoms can influence the satisfaction with a donation[37] and HRQoL.[38] Our findings suggested that when physical discomfort interfered with daily activities, the risk of fearing kidney failure increased. This effect was further increased when the neuroticism score was high. Neuroticism also increases the risk of impaired HRQoL after a donation.[39] Thus, the combination of neuroticism and disabling physical discomfort might prevent the negative expectations that underlie fears from declining normally with time. This combination might even counteract the reassuring medical feedback given to LKDs. Furthermore, it remains uncertain whether the effect of the physical component on HRQoL can be completely attributed to donation-related physical symptoms. In our study, some LKDs with high FKFQ scores had donated more than 8 years before this study; thus, it was unlikely that their physical discomfort was related to the donation. Some

LKDs might misinterpret subsequent physical problems as negative outcomes of a donation,[40] and this misinterpretation could lead to anxiety.[41] Increased neuroticism in an LKD might potentiate the misinterpretation of physical symptoms by taking them as indications of kidney failure. This issue might be addressed by administering a qualitative assessment to determine the meaning attributed by LKDs to persistent physical symptoms after a donation (SDC, Summary of relationships between variables, http://links.lww.com/TXD/A302).

The FKFQ score was unrelated to extraversion or optimism. These personality dimensions promote positive affects and resilience when facing stressful circumstances. The excellent outcomes observed in most kidney donations might explain the low influence of positive affectivity in a scenario where resilience is not necessary.

As previously observed,[37] unfavorable perceptions of the recipient's health status did not influence the LKD's FKF. Negative outcomes were infrequent among our recipients; thus, the preponderant perception that the recipients were in good health might have reduced the predictive power of this variable.

A strength of our study was the high response rate. Thus, a potential nonresponse bias (eg, participants missed are those who suffered adverse outcomes) would not have affected the results substantially.

Limitations

General population participants were recruited from university students and their relatives and acquaintances, which led to differences in educational level, age, and civil status between this group and LKDs. These variables did not differentiate LKDs with the highest FKF. However, an older age and being married might protect against the development of FKF.[9] Therefore, future studies comparing LKDs and the general population might recruit matched cohorts.

We did not assess the influence of recipients' and LKDs' comorbidities, risk factors (eg, hypertension), or kidney function on the FKF. Futures studies might include these potentially relevant variables.

The original validation of the FKFQ found that LKDs were more likely to have moderate/high FKFQ scores when they were genetically related to their recipients.[10] However, we did not observe a high proportion of genetically related recipients among LKDs with the highest FKFQ scores. This result might have been influenced by a potential lack of statistical power. Conversely, LKDs might not have been influenced by genetic relationships because they were well informed about the low risk associated with the genetic link between donor and recipient (eg, in 1 study on 3698 donors, only 3 of 11 LKDs who became ill had the same kidney disease cause as their sibling).[42] However, we did not assess the information received by donors or their understanding of the risk of kidney failure.

Very few LKDs believed that the medical monitoring was insufficient. This result suggested that the FKF might not be ameliorated by increasing the degree of medical monitoring. However, our sample might have been too small to detect the influence of medical monitoring. A sample with a higher proportion of LKDs that feel insufficiently monitored might reveal an influence of this variable.

We did not assess whether donors felt that the donation was meaningful or purposeful. This variable could protect against health-related distress,[43] and its absence could be a

risk factor for anxiety.[44] We did not assess other sources of anxiety, such as donation-related financial costs.

Another study limitation was the retrospective, cross-sectional design. For example, we could not determine whether the FKF was resistant to spontaneous adjustment,[10] although other health-related fears were shown to be quite stable.[45] The main predictor of the FKFQ scores was neuroticism, a stable personality characteristic, and the study comprised an 11-year period of donations. However, these features did not provide evidence on the stability of the FKF. Future prospective studies might define the time it takes to develop a FKF, identify which donors with a FKF might develop a healthy adjustment, and assess which confident donors later become afraid of losing their kidney. Those studies might be able to adapt the kidney failure scenario to previously identified triggers of fear of recurrence. For example, potential triggers might include knowledge of graft loss cases, media references to negative posttransplantation outcomes, or the presence of persistent physical symptoms, such as pain and fatigue (also identified as a trigger in the present study).[30,46]

In conclusion, the Spanish FKFQ showed acceptable psychometric properties and could be used to assess Spanish-speaking LKDs. Donors with high neuroticism that experience postdonation physical symptoms that interfere with daily activities appeared to be at high risk of fearing the failure of their remaining kidney.

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