

# Emotional and Financial Experiences of Kidney Donors over the Past 50 Years: The RELIVE Study

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## Abstract

**Background and objectives** Most kidney donors view their experience positively, but some may experience psychosocial and financial burdens. We hypothesized that certain donor characteristics, poor outcome of the recipient, negative perceptions of care, and lack of support may be associated with poor psychosocial outcomes for donors.

**Design, setting, participants, & measurements** The Renal and Lung Living Donors Evaluation Study (RELIVE) examined long-term medical and psychosocial outcomes for kidney donors (at three U.S. transplant centers) who donated between 1963 and 2005. Standardized questionnaires evaluated donor perspectives, recovery time, social support, motivation, financial impact, insurability after donation, and current psychological status. Questionnaires were mailed to 6909 donors.

**Results** Questionnaires were returned by 2455 donors, who had donated  $17 \pm 10$  years earlier (range, 5–48 years), a response rate of 36%. Most (95%) rated their overall donation experience as good to excellent. Rating the overall donor experience more negatively was associated with donor complications, psychological difficulties, recipient graft failure, and longer time since donation. Nine percent ( $n=231$ ) reported one or more of the following poor psychosocial outcomes: fair or poor overall donor experience, financial burden, regret or discomfort with decision to donate, or psychological difficulties since donation. Recipient graft failure was the only predictor for reporting one or more of these poor psychosocial outcomes (odds ratio, 1.77; 95% confidence interval, 1.33 to 2.34). Donors with lower educational attainment experienced greater financial burden. One of five employed donors took unpaid leave; 2% reported health and life insurability concerns.

**Conclusions** Although the majority of donors viewed their overall donation experience positively, almost 1 in 10 donors reported at least one negative consequence related to donation. Recipient graft failure was associated with poor psychosocial outcome, defined as one or more of these negative consequences. Some donors were financially disadvantaged, and some experienced insurance difficulties. Interventions to avoid negative psychosocial and financial consequences are warranted.

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## Introduction

Most kidney donors experience psychosocial benefits, including improved self-esteem and donor-recipient relationships (1–5); likewise, most report no regrets (6,7) and reaffirm their decision to donate (3,8–13). However, these experiences are not universal. Predonation ambivalence, compromised mental health, strained relationship with the recipient, lack of financial resources, and pressure regarding donation are associated with poor psychological outcomes (14–22). Postdonation factors, such as lack of support, complications, or lack of health insurance, may prevent donors from seeking recommended medical or psychological follow-up, further interfering with recovery. Known psychosocial risks after surgery must be revealed during the education process in an attempt to avoid problems afterward and assure

informed consent. Consequently, it is critical that transplant centers collect this information after donation and attend to those needing intervention.

Most data regarding this topic come from single-center studies with small numbers and limited follow-up. An exception is the Renal and Lung Living Donors Evaluation Study (RELIVE), which examined the medical and psychosocial status of 2455 kidney donors at three major U.S. transplant centers, who donated between 1963 and 2005, from questionnaires and examinations completed 5–48 years after donation; quality of life results for this cohort have been reported (23). We hypothesized that a poor psychosocial outcome (e.g., rating the overall donation experience negatively or recalling adverse psychological or financial effects, discomfort, or regret about decision to donate) would be associated with certain

Due to the number of contributing authors, the affiliations are provided in the Supplemental Material.

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donor characteristics, negative recipient outcome, and negative perceptions of support.

## Materials and Methods

### Questionnaire and Ethical Considerations

Eligible participants donated between June 1963 and June 2005 at the University of Minnesota, Minneapolis, Minnesota; Mayo Clinic, Rochester, Minnesota; and the University of Alabama, Birmingham, Alabama (Supplemental Figure 1). Demographic characteristics were collected by chart review. A packet was mailed to 6909 donors believed to be living (of an original cohort of 8951 donors); the packet included a cover letter, consent form, and 11-page questionnaire. Nonrespondents were mailed a second packet at 4 weeks; they were called if they hadn't returned the packet after another 2 weeks. Efforts to obtain correct contact information for nonresponding donors were made through the Social Security system. Data were collected between 2010 and 2012.

The questionnaire evaluated psychosocial, financial, and donor-specific outcomes after nephrectomy. Questions emphasized donor experience, recovery, current psychological status, motivation, interpersonal relationship with recipient, support available, financial effects, and long-term insurability. Questions were adapted from previous donor surveys, including studies by the authors (8,23), and the extensive donor research conducted by Simmons *et al.* (14). For this analysis, we grouped the following individual responses as a composite endpoint to define "poor psychosocial outcome": (1) fair or poor overall donation experience; (2) great or extreme financial burden due to donation; (3) probably or definitely would not donate again in response to a hypothetical question; (4) emotional, psychological, or substance use difficulty because of donation; or (5) somewhat or very uncomfortable with decision to donate. We assessed clarity, relevance, and validity of our questionnaire through cognitive interviewing in a RELIVE pilot study with a diverse sample of donors. (See Supplemental Material; study details are available elsewhere [24–26].)

The institutional review board approved the study sites and the data coordinating center; participants provided written informed consent.

### Statistical Analyses

Donor and recipient demographic data are presented as frequencies and percentages for categorical outcomes or as means  $\pm$  SDs for continuous variables. Wilcoxon rank-sum tests compared groups, and multivariable models examined relationships between demographic characteristics and donor perceptions. Logistic, multinomial, and linear regression analyses were performed to identify variables associated with donor outcomes. Independent variables were donation age, time (years from donation), sex, race, educational attainment at donation, recipient death or graft failure, relationship to recipient, surgical procedure, and donor-reported complications. To create models, we used a best subsets approach; the final models were selected on the basis of model fit, explained variance, and statistical significance of predictors.

Multiple imputation methods were used for regression covariates with missing data (27). SEMs of multiple

imputed data were increased to account for additional uncertainty, thus minimizing the chance of making incorrect inferences. Statistical data analyses were performed using SAS software, version 9.2 (28). Results were considered statistically significant at  $P < 0.01$ .

## Results

### Donor Characteristics

Among 8951 kidney donors, 6909 were thought to be alive and to have donated on or before June 30, 2005. Of the 6909 eligible donors, 14% (938) had no current address and 36% (2501) did not respond to the invitation to participate (totaling 3439). Of the remaining 3470 eligible donors, 2455 (36% of the 6,909) returned the questionnaire (enrollment details in Supplemental Figure 1). All nonparticipants ( $n=3516$ ) had lower educational attainment at donation (odds ratio [OR], 0.75; 95% confidence interval [CI], 0.70 to 0.80); were younger at donation (OR, 0.98; 95% CI, 0.98 to 0.99); and were more likely to be black (OR, 2.43; 95% CI, 1.95 to 3.03), male (OR, 1.28; 95% CI, 1.15 to 1.43), and related to their recipient (OR, 1.72; 95% CI, 1.43 to 2.07) compared with participants ( $n=2455$ ).

Most respondents were white (93%) and women (61%) and were related to their recipient (78%) (Table 1). The mean time from donation was  $17 \pm 10$  years (range, 5–48 years); 30% donated before 1990, 32% from 1990 to 1999, and 38% from 2000 to 2005. Most (79%) were  $< 50$  years of age at donation, and the average age was  $58 \pm 11$  years at survey completion. Respondents were highly educated; 37% had some post-high school education, 21% had a 4-year college degree, and 18% had a postgraduate degree. Most (75%) lived with a spouse or significant other.

### Donor Health Status

While most donors (80%) had no medical complications, 8% reported a longer hospitalization than expected or readmission, and 14% reported outpatient medical problems (Table 2). Eighty-seven (4%) reported active treatment for donor-related concerns. Ninety-nine donors (4%) attributed emotional, psychological, or substance use difficulties to donation; of these, nearly a third (29%) had a pre-donation history of psychiatric conditions or substance abuse, and 2% continued receiving psychiatric care for issues attributed to donation.

### Recipient Status

Almost all (99%) respondents knew their recipient's status and kidney function (Tables 1 and 2): Forty-seven percent reported their recipient was alive with kidney function, 12% reported the kidney was not functioning but recipient was alive, and 39% reported their recipient had died.

### Primary Reason for Donation

Most (91%) were motivated by love for their recipient, 72% said donation was a logical response, 42% were influenced by faith, and 37% believed it was their moral obligation (Supplemental Figure 2).

However, 10% donated because family or friends expected them to, 5% felt pressure to donate, and 12% felt pressure not to donate. Siblings were most likely to feel pressure to donate ( $z$  score, 6.43;  $P < 0.001$ ). Unrelated

Table 1. Donor and recipient characteristics	
Characteristic	Questionnaire Respondents, n (%) (n=2455)
<b>At time of donation</b>	
Age	
15–29 yr	505 (20.6)
30–59 yr	1851 (75.4)
60–74 yr	99 (4.0)
Race	
American Indian	16 (0.7)
Asian American	11 (0.4)
Black	113 (4.6)
White	2282 (93.0)
Multiracial	20 (0.8)
Female	1505 (61.3)
<b>Donor relationship to recipient</b>	
Parent	450 (18.3)
Child	316 (12.9)
Sibling	1011 (41.2)
Other relative	130 (5.3)
Spouse/partner	219 (8.9)
Friend	173 (7.0)
Paired exchange	4 (0.2)
Other unrelated	145 (5.9)
<b>Year of donation</b>	
1963–1969	28 (1.1)
1970–1979	275 (11.2)
1980–1989	443 (18.0)
1990–1999	775 (31.6)
2000–2005	934 (38.0)
<b>Employment status</b>	
Working full-time	1777 (72.4)
Working part-time	225 (9.2)
Retired	67 (2.7)
Unemployed	142 (5.8)
Unknown	244 (9.9)
<b>Surgical procedure</b>	
Open	1630 (66.4)
Laparoscopic	822 (33.5)
Unknown	3 (0.1)
<b>At time of questionnaire</b>	
Age	
24–29 yr	20 (0.8)
30–59 yr	1423 (58.0)
60–79 yr	947 (38.6)
80–94 yr	65 (2.6)
<b>Educational attainment</b>	
<High school	66 (2.7)
High school	497 (20.2)
Some college, vocational/technical school, or associates degree	920 (37.5)
4-yr college degree	510 (20.8)
Graduate degree	449 (18.3)
<b>Marital status</b>	
Married or living together	1852 (75.4)
Separated, divorced or widowed	449 (18.3)
Never married	141 (5.7)
<b>Employment status</b>	
Working full-time	1272 (51.8)
Working part-time	299 (12.2)
Not working for pay	770 (31.4)
Unemployed	80 (3.3)
Unknown	34 (1.4)

Table 1. (Continued)	
Characteristic	Questionnaire Respondents, n (%) (n=2455)
<b>Recipient status reported by donor</b>	
Alive	1468 (59.8)
<b>Graft status</b>	
Functioning	1060 (43.2)
Functioning, but with problems	100 (4.1)
Not functioning (graft failure)	307 (12.5)
Numbers and percentages may not add up to the sample total because of missing data.	

donors were more likely to feel pressure from others not to donate (z score, 9.14;  $P < 0.001$ ).

In a multinomial regression, those asked to donate by their recipient (17%) were more likely related to the recipient (OR, 2.18; 95% CI, 1.42 to 3.35), male (OR, 1.49; 95% CI, 1.20 to 1.85), and longer out from donation (OR, 1.20; 95% CI, 1.07 to 1.34) compared with those autonomously initiating donation (79%) (Table 3).

**Recovery Time**

The majority (92%) reported returning to functional activities (i.e., daily routine obligations) within 3 months, but only 73% reported nephrectomy recovery within 3 months. Five percent needed >6 months to recover while 0.4% said they never fully recovered (Table 2). Shorter recovery time was reported by white donors ( $\beta = -0.13$ ; 95% CI,  $-0.22$  to  $-0.04$ ) and those who underwent laparoscopic nephrectomy ( $\beta = -0.10$ ; 95% CI,  $-0.15$  to  $-0.05$ ). Results are the equivalent of a recovery time of 1.31 points (on a 4-point scale) for a white donor versus 1.44 points for a nonwhite donor and a recovery time of 1.25 points (on a 4-point scale) for a donor with a laparoscopic procedure versus 1.35 points for a donor with an open procedure. Additional interpretations of regression results are presented in the Supplemental Material. Daily activities were resumed sooner by white donors ( $\beta = -0.16$ ; 95% CI,  $-0.21$  to  $-0.11$ ) and those with higher educational attainment ( $\beta = -0.02$ ; 95% CI,  $-0.03$  to  $0.00$ ) (Table 3). Recovery time shorter than expected was experienced by men ( $\beta = -0.15$ ; 95% CI,  $-0.24$  to  $-0.05$ ) and those who underwent laparoscopic nephrectomy ( $\beta = -0.24$ ; 95% CI,  $-0.34$  to  $-0.14$ ).

**Social Support**

Six percent of donors felt they lacked support from family and friends during donation. Related donors were more likely than unrelated donors to feel family or friends' support ( $\beta = 0.17$ ; 95% CI, 0.07 to 0.27). Donors experiencing emotional difficulty related to donation were less likely to feel supported by family or friends ( $\beta = -0.39$ ; 95% CI,  $-0.54$  to  $-0.23$ ). Of employed donors, 82% felt their employer was supportive.

Sixty-two percent of donors felt that health care providers were supportive after surgery, 20% did not, and 17%

Table 2. Summary of positive, negative, and neutral perceptions related to donation (n=2455)

Positive Outcomes		Neutral Responses		Negative Outcomes		Unknown, %
Outcome	Respondents, %	Outcome	Respondents, %	Outcome	Respondents, %	
<b>Donor health status</b>						
No medical complications	80		0	≥1 <b>medical complication</b>	20	<1
				Medical complication that did not require hospitalization	14	
				Prolonged hospitalization or readmission	8	
				Currently seeing a doctor for donation-related concerns	4	
No emotional, psychological, or substance abuse difficulty	95		0	<b>Emotional, psychological, or substance use difficulty</b>	4	1
				Currently receiving treatment for emotional, psychological, or substance use difficulty	2	
<b>Recipient status</b>						
Alive with functioning graft	47		NA	Alive without function of donor's kidney (graft failure)	12	1
				Deceased	39	
Did not have complications	52		NA	Had complications	40	8
<b>Reasons for donation</b>						
Did not feel pressured to donate	88	Neutral	7	Felt pressured to donate	5	1
Did not feel pressured to not donate	82	Neutral	5	Felt pressured to not donate	12	1
<b>Recovery time</b>						
Returned to usual activities within 3 mo	92	Returned to usual activities in 3–6 mo	6	<b>Longer return</b>	1	<1
				Return to usual activities in >6 mo	1	
Recovered within 3 mo	73	Recovered in 3–6 mo	21	Never returned to usual activities	<1	<1
				<b>Longer recovery</b>	6	
				Recovery took >6 mo	5	
				Never recovered	<1	
<b>Social support</b>						
Family and friends were supportive	94	Neutral	2	Family and friends were not supportive	4	1
Employer was supportive <sup>a</sup>	82	Neutral <sup>a</sup>	12	Employer was not supportive <sup>a</sup>	4	2
Health care providers were supportive	62	Neutral	17	Health care providers were not supportive	20	1
Donor received attention after surgery	85	Neutral	6	No one paid attention to donor after surgery	9	<1

**Table 2. (Continued)**

Outcome	Positive Outcomes		Neutral Responses		Negative Outcomes		Unknown, %
	Respondents, %	Outcome	Respondents, %	Outcome	Respondents, %	Outcome	
<b>Current relationship with recipient</b>							
Positive effect on relationship with recipient <sup>a</sup>	75	Neutral <sup>a</sup>	22	Negative effect on relationship with recipient <sup>a</sup>	2	1	
Feel closer to the recipient <sup>b</sup>	79	Neutral <sup>b</sup>	9	Feel less close to the recipient <sup>b</sup>	11	1	
Donor does not think the recipient feels indebted <sup>b</sup>	55	Neutral <sup>b</sup>	17	Donor thinks the recipient feels indebted <sup>b</sup>	28	1	
Recipient shows adequate gratitude <sup>b</sup>	88	Neutral <sup>b</sup>	5	Recipient does not show adequate gratitude <sup>b</sup>	7	1	
<b>Perceived experience</b>							
Good, very good, or excellent overall donation experience	95	Neutral	NA	Fair or poor donation experience	5	1	
Comfortable with decision to donate	96	Neutral	2	Uncomfortable with decision to donate	1	1	
Would donate again if possible	94	Neutral	3	Would not donate again	1	1	
Donor disagrees that he/she sometimes wishes he/she would not have donated	93	Neutral	3	Donor agrees with statement “I sometimes wish I would not have donated.”	4	1	
Positive effect on recipient’s general health <sup>a</sup>	92	Neutral <sup>a</sup>	3	Negative impact on recipient’s general health <sup>a</sup>	4	1	
Positive effect on relationships with other people involved in the donation	59	Neutral	38	Negative effect on relationships with other people involved in the donation	3	1	
Positive effect on donor’s own life	56	Neutral	42	Negative effect on donor’s own life	2	<1	
Positive effect on donor’s view of him/herself as a person	50	Neutral	49	Negative effect on donor’s view of self as a person	1	<1	
Positive effect on donor’s meaning of life	65	Neutral	33	Negative effect on donor’s meaning of life	<1	1	

Percentages do not include unknown values, responses of “I don’t know,” and NA (not applicable) questions; when the numbers do not add up to 100% within a row, some responses were unknown and/or missing.

<sup>a</sup>Among donors to whom the questions were applicable.

<sup>b</sup>Among donors whose recipients were alive at the time of the questionnaire.

Table 3. Results of multivariable models predicting donation related outcomes			
Outcome/Predictors (with Ordered Response Options)	Estimate or OR (95% CI)	P Value	Model Fit
<b>Reasons for donating (reference group is "I volunteered to donate on my own")<sup>a</sup></b>			C-statistic=NA
Response: "I was asked by someone other than my recipient"			
Time since donation, per 10 yr	1.71 (1.41–2.08)	<0.001	
Male (ref: female)	1.62 (1.08–2.44)	0.02	
Relation to recipient: parent, child, sibling, spouse, other relative (ref: not related)	1.33 (0.59–3.01)	0.50	
Response: "I was asked by my recipient"			
Time since donation, per 10 yr	1.20 (1.07–1.34)	0.001	
Male (ref: female)	1.49 (1.20–1.85)	<0.001	
Relation to recipient: parent, child, sibling, spouse, other relative (ref: not related)	2.18 (1.42–3.35)	<0.001	
<b>Overall recovery time (&lt;3 mo, 3–6 mo, &gt;6 mo, never recovered)</b>			R <sup>2</sup> =0.01
Race: white (ref: nonwhite)	−0.13 (−0.22 to −0.04)	0.005	
Surgical procedure: laparoscopic (ref: open)	−0.10 (−0.15 to −0.05)	<0.001	
<b>Recovery time for daily activities (&lt;3 mo, 3–6 mo, &gt;6 mo, never returned to usual activities)</b>			R <sup>2</sup> =0.02
Race: white (ref: nonwhite)	−0.16 (−0.21 to −0.11)	<0.001	
Educational attainment at donation	−0.02 (−0.03 to 0.00)	0.009	
<b>Recovery time compared with expectations (much shorter than, somewhat shorter than, about as long as, somewhat longer than, much longer than I expected)</b>			R <sup>2</sup> =0.02
Age at donation, per 10 yr	0.44 (0.19–0.68)	0.004	
Age at donation, per 10 yr, squared	−0.06 (−0.09 to −0.03)	<0.001	
Male (ref: female)	−0.15 (−0.24 to −0.05)	0.002	
Surgical procedure: laparoscopic (ref: open)	−0.24 (−0.34 to −0.14)	<0.001	
<b>Felt supported by friends and family (strongly disagree, disagree, unsure, agree, strongly agree)</b>			R <sup>2</sup> =0.02
Time since donation, per 10 yr	−0.07 (−0.11 to −0.04)	<0.001	
Relation to recipient: parent, child, sibling, spouse, other relative (ref: not related)	0.17 (0.07–0.27)	<0.001	
Donor had at least one emotional, psychological, or substance abuse difficulty after donation	−0.39 (−0.54 to −0.23)	<0.001	
<b>Felt supported by health care providers (strongly disagree, disagree, unsure, agree, strongly agree)</b>			R <sup>2</sup> =0.04
Age at donation, per 10 yr	0.07 (0.03–0.11)	0.001	
Male (ref: female)	0.16 (0.07–0.26)	0.001	
Donor had at least one medical complication after donation	−0.31 (−0.43 to −0.19)	<0.001	
Donor had at least one emotional, psychological, or substance abuse difficulty after donation	−0.68 (−0.90 to −0.45)	<0.001	
<b>Felt no one paid attention (strongly disagree, disagree, unsure, strongly agree, agree)</b>			R <sup>2</sup> =0.03
Donor had at least one medical complication after donation	0.27 (0.17–0.37)	<0.001	
Donor had at least one emotional, psychological, or substance abuse difficulty after donation	0.66 (0.47–0.85)	<0.001	
<b>Feels closer to the recipient since donating (of donors with living recipients) (strongly disagree, disagree, unsure, strongly agree, agree)</b>			R <sup>2</sup> =0.04
Age at donation to per 10 yr	0.08 (0.03–0.13)	0.001	
Donor had at least one emotional, psychological, or substance abuse difficulty after donation	−0.58 (−0.87 to −0.28)	<0.001	
Donor type: Parent (ref: other unrelated)	0.56 (0.33–0.79)	<0.001	
Child	0.61 (0.35–0.88)	<0.001	
Sibling	0.35 (0.13–0.57)	0.002	
Spouse	0.55 (0.29–0.81)	<0.001	
Other	0.33 (0.05–0.62)	0.02	
Friend	0.46 (0.20–0.73)	<0.001	

Outcome/Predictors (with Ordered Response Options)	Estimate or OR (95% CI)	P Value	Model Fit
<b>Thinks recipient feels indebted (strongly disagree, disagree, unsure, strongly agree, agree)</b>			R <sup>2</sup> =0.05
Donor type: Parent (ref: other unrelated)	-0.69 (-0.97 to -0.41)	<0.001	
Child	-0.28 (-0.60 to 0.04)	0.08	
Sibling	-0.22 (-0.48 to 0.05)	0.11	
Spouse	-0.42 (-0.74 to -0.11)	0.01	
Other	-0.26 (-0.60 to 0.09)	0.14	
Friend	-0.02 (-0.34 to 0.31)	0.93	
Donor kidney is no longer functioning for the recipient (ref: is functioning)	-0.32 (-0.47 to -0.16)	<0.001	
<b>Thinks recipient does not show enough gratitude (strongly disagree, disagree, unsure, agree, strongly agree)</b>			R <sup>2</sup> =0.06
Age at donation, per 10 yr	-0.09 (-0.13 to -0.04)	<0.001	
Donor had at least one medical complication after donation	0.32 (0.20–0.44)	<0.001	
Donor had at least one emotional, psychological, or substance abuse difficulty after donation	0.63 (0.36–0.90)	<0.001	
Donor type: Parent (ref: other unrelated)	-0.24 (-0.45 to -0.03)	0.02	
Child	-0.33 (-0.58 to -0.09)	0.007	
Sibling	-0.13 (-0.33 to 0.06)	0.09	
Spouse	-0.03 (-0.27 to 0.21)	0.79	
Other	-0.17 (-0.42 to 0.09)	0.20	
Friend	-0.25 (-0.50 to -0.01)	0.04	
<b>Overall donation experience (poor, fair, good, very good, excellent)</b>			R <sup>2</sup> =0.11
Time since donation, per 10 yr	-0.05 (-0.09 to -0.01)	0.008	
Donor had at least one medical complication after donation	-0.49 (-0.57 to -0.40)	<0.001	
Donor had at least one emotional, psychological, or substance abuse difficulty after donation	-0.93 (-1.09 to -0.76)	<0.001	
Donor kidney is no longer functioning for the recipient (ref: is functioning)	-0.11 (-0.18 to -0.04)	0.003	
<b>If possible, would donate again (definitely not, probably not, not sure, probably yes, definitely yes)</b>			R <sup>2</sup> =0.04
Time since donation, per 10 yr	-0.04 (-0.06 to -0.01)	0.003	
Race: white (ref: non-white)	0.14 (0.05–0.22)	0.002	
Relation to recipient: parent, child, sibling, spouse, other relative (ref: not related)	0.10 (0.03–0.17)	0.005	
Donor had at least one medical complication after donation	-0.09 (-0.15 to -0.03)	0.002	
Donor had at least one emotional, psychological, or substance abuse difficulty after donation	-0.44 (-0.55 to -0.33)	<0.001	
<b>Difficulty paying monthly household bills<sup>a</sup> (no, yes)</b>			C-statistic=0.75
Age at donation, per 10 yr	0.62 (0.51–0.75)	<0.001	
Time since donation, per 10 yr	0.75 (0.60–0.93)	0.009	
Educational attainment at donation	0.58 (0.46–0.73)	<0.001	
Donor had at least one medical complication after donation	2.21 (1.46–3.34)	<0.001	
Donor had at least one emotional, psychological, or substance abuse difficulty after donation	4.30 (2.48–7.46)	<0.001	
<b>Donation caused a financial burden (no burden, little burden, moderate burden, great burden, extreme burden)</b>			R <sup>2</sup> =0.07
Age at donation, per 10 yr	-0.05 (-0.07 to -0.02)	<0.001	
Educational attainment at donation	-0.06 (-0.08 to -0.03)	<0.001	
Donor had at least one medical complication after donation	0.18 (0.11–0.25)	<0.001	
Donor had at least one emotional, psychological, or substance abuse difficulty after donation	0.65 (0.52–0.78)	<0.001	

**Table 3. (Continued)**

Outcome/Predictors (with Ordered Response Options)	Estimate or OR (95% CI)	P Value	Model Fit
<b>Poor psychosocial outcome (defined as having at least one of the following: fair/poor overall donation experience; great/extreme financial burden due to donation; probably/definitely not donate again; emotional, psychological or substance abuse use difficulty due to donation; or discomfort with decision to donate)<sup>a</sup></b>			C-statistic=0.57
Donor kidney is no longer functioning for the recipient (ref: functioning)	1.77 (1.33–2.34)	<0.001	
OR, odds ratio; 95% CI, 95% confidence interval; ref, reference; NA, not available.			
<sup>a</sup> Modeled using binary logistic or multinomial logistic regression; statistics reported are ORs and 95% CIs. Models not marked with the "a" footnote used linear regression, and statistics reported are $\beta$ coefficients and 95% CIs. When assessing the fit of a binary (but not available for multinomial) logistic regression, a c-statistic of 0.5 indicates prediction no better than chance, whereas a c-statistic of 1.0 indicates perfect prediction of the outcome. Multinomial logistic regressions do not provide a c-statistic. In linear regression, $R^2$ is the proportion of variance of the outcome that is explained by the predictor variables; $R^2$ ranges between 0 (no prediction) and 1 (perfect prediction). Estimates from linear regressions can be interpreted as the difference in the outcome per one-unit higher value in the predictor. For instance, the $-0.13$ estimate for race in the model predicting overall recovery time indicates that white donors recovered 1/8 point faster on a 4-point scale relative to nonwhite donors. Without adjustment for surgical procedure, 74% of white donors recovered within 3 months, compared with 67% of nonwhite donors. ORs can be interpreted as the difference in the odds of the outcome, per one unit higher value in the predictor. For example, the odds of donors with at least one medical complication having difficulty paying household bills are 121% higher (OR, 2.21) than the odds of donors without a medical complication having difficulty paying household bills.			

were unsure. Older donors ( $\beta=0.07$ ; 95% CI, 0.03 to 0.11) and men ( $\beta=0.16$ ; 95% CI, 0.07 to 0.26) felt more support from health care providers. Nine percent agreed that "nobody paid much attention" to them after donation. Donors reporting postoperative medical complications ( $\beta=-0.31$ ; 95% CI,  $-0.43$  to  $-0.19$ ) or emotional difficulties ( $\beta=-0.68$ ; 95% CI,  $-0.90$  to  $-0.45$ ) were less likely to feel support from health care providers.

### Current Donor-Recipient Relationship

Most donors (75%) felt that donation had positively influenced their relationship with their recipient (Table 2). Of donors whose recipient was still alive, most (79%) felt closer to them, 28% believed their recipients felt indebted to them, and 7% believed their recipient did not show enough gratitude.

Predictors of outcomes regarding the donor-recipient relationship are shown in Table 3. Respondents who were older at donation felt closer to their recipient after nephrectomy ( $\beta=0.08$ ; 95% CI, 0.03 to 0.13) and were less likely to feel that their recipient did not show enough gratitude ( $\beta=-0.09$ ; 95% CI,  $-0.13$  to  $-0.04$ ).

Feeling closer to the recipient was less common among donors experiencing emotional difficulty after donation ( $\beta=-0.58$ ; 95% CI,  $-0.87$  to  $-0.28$ ). Donors were more inclined to feel that their recipient did not adequately show gratitude if they experienced a medical complication ( $\beta=0.32$ ; 95% CI, 0.20 to 0.44) or emotional difficulty ( $\beta=0.63$ ; 95% CI, 0.36 to 0.90) after donation. Donors who were offspring ( $\beta=0.61$ ; 95% CI, 0.35 to 0.88), parents ( $\beta=0.56$ ; 95% CI, 0.33 to 0.79), siblings ( $\beta=0.35$ ; 95% CI, 0.13 to 0.57), spouses ( $\beta=0.55$ ; 95% CI, 0.29 to 0.81), or friends ( $\beta=0.46$ ; 95% CI, 0.20 to 0.73) claimed that their

relationship with their recipient grew stronger compared with unrelated donors (Table 3).

Parental ( $\beta=-0.69$ ; 95% CI,  $-0.97$  to  $-0.41$ ) and spousal ( $\beta=-0.42$ ; 95% CI,  $-0.74$  to  $-0.11$ ) donors were least likely to think their recipient felt indebted; children who donated to parents felt their recipients showed gratitude ( $\beta=-0.33$ ; 95% CI,  $-0.58$  to  $-0.09$ ). Donors whose recipients had a graft that no longer functioned reported that the recipients felt less indebted than recipients with graft function or whose graft status was unknown ( $\beta=-0.32$ ; 95% CI,  $-0.47$  to  $-0.16$ ).

### Perceived Overall Experience

Most donors (95%) rated their overall donor experience as good to excellent (Supplemental Figure 3). Table 3 demonstrates that donors with medical complications ( $\beta=-0.49$ ; 95% CI,  $-0.57$  to  $-0.40$ ) or emotional difficulty ( $\beta=-0.93$ ; 95% CI,  $-1.09$  to  $-0.76$ ) and those who donated longer ago ( $\beta=-0.05$ ; 95% CI,  $-0.09$  to  $-0.01$ ) rated their experience more negatively. Donors whose graft still functioned or who did not know the graft status were the most positive about their overall donation experience ( $\beta=-0.11$ ; 95% CI,  $-0.18$  to  $-0.04$ ).

Most (96%) were comfortable with their decision to donate; 94% would donate again, but 1.2% would probably, or definitely, not donate again. The decision to donate was more often affirmed by white donors ( $\beta=0.14$ ; 95% CI, 0.05 to 0.22) and by related donors ( $\beta=0.10$ ; 95% CI, 0.03 to 0.17) (Table 3). Those less likely to affirm their donation decision were donors with a medical complication ( $\beta=-0.09$ ; 95% CI,  $-0.15$  to  $-0.03$ ), an emotional difficulty ( $\beta=-0.44$ ; 95% CI,  $-0.55$  to  $-0.33$ ), or donated longer ago ( $\beta=-0.04$ ; 95% CI,  $-0.06$  to  $-0.01$ ) (Table 3).

Donors felt donation had positive effects on their recipient's general health (92%), their own meaning of life (65%), and self-perception (50%) (Supplemental Figure 4).

### Financial Experience

Some donors (5%) reported problems paying routine monthly household bills (Table 4). Donation caused financial burden to 20% of donors. Greater financial problems were more likely in those with medical complications ( $\beta=0.18$ ; 95% CI, 0.11 to 0.25) or emotional difficulty ( $\beta=0.65$ ; 95% CI, 0.52 to 0.78). Problems covering monthly bills were more likely in recent donors (OR, 0.75; 95% CI, 0.60 to 0.93). Older donors and those with higher education were less likely to have difficulty paying household bills (OR, 0.62 [95% CI, 0.51 to 0.75] and 0.58 [95% CI, 0.46–0.73], respectively) and experienced less financial burden ( $\beta=-0.05$  [95% CI,  $-0.07$  to  $-0.02$ ] and  $-0.06$  [95% CI,  $-0.08$  to  $-0.03$ ], respectively).

Nearly 20% of donors (18.8%) took unpaid work leave. Some reported negative impacts on insurability: 1.8% were denied health insurance and 2.1% were denied life insurance (Table 4). Problems paying donor-related medical bills were reported by 1.7%.

### Predictors of Poor Psychosocial Outcome

Separately from rating just the overall donor experience (above), we defined a poor psychosocial outcome as when one or more of the following was reported: (1) fair or poor overall donation experience ( $n=114$ ); (2) great or extreme financial burden due to donation ( $n=45$ ); (3) probably or definitely would not donate again ( $n=29$ ); (4) emotional, psychological, or substance use difficulty because of donation ( $n=99$ ); or (5) somewhat or very uncomfortable with decision to donate ( $n=27$ ). In total, 231 donors (9%) met this definition. Of these, 172 (74%) reported a single area, 42 (18%) reported two, 10 (4%) reported three, seven (3%) reported four, and no donor experienced all five. Nearly half (49%) of the donors (114 of 231) with a poor psychosocial outcome by this composite variable rated their overall donation experience as fair or poor. The only factor associated with the composite poor psychosocial outcome variable was recipient graft failure (OR, 1.77; 95% CI, 1.33 to 2.34) (Table 3).

### Discussion

Our results reaffirm that most living kidney donors had a positive donor experience, were satisfied with their decision to donate, didn't feel pressured, and were not negatively affected over time. Nevertheless, some reported adverse psychosocial and financial consequences related to donation.

A few donors felt pressure to donate; they were more likely to be siblings, consistent with prior reports (9,23,29,30). Unrelated donors felt pressure not to donate. Resistance to donation by others may occur when individuals don't know their recipient or are without direct attachment or benefit (31,32). Assessing levels of pressure in these two groups might be heightened.

Fewer than 10% of donors experienced one or more of the negative psychosocial or financial consequences that made up our definition of poor psychosocial outcome, and

**Table 4. Donors reporting financial issues related to donation**

Because of donation. . .	Yes, %
My health insurance premium increased	1.2
I was denied health insurance	1.8
My life insurance premium increased	1.7
I was denied life insurance	2.1
I had problems paying medical bills	1.7
I had problems paying household/routine monthly bills	4.8
I took unpaid leave from work	18.8
Percentages among donors with nonmissing data.	

recipient graft failure, the only predictor of this composite outcome, is unknown before donation.

In addition, unrelated donors and those with emotional difficulty after donation were more likely to feel unsupported. The finding regarding unrelated donors is crucial because living donor transplants among individuals with no prior relationship to their recipient continue to increase (e.g., public solicitations, nondirected donations).

The Organ Procurement and Transplantation Network policy requires that centers complete follow-up surveys on each donor (33). Data related to medical/psychological complications, lifestyle changes, and financial impact can be collected simultaneously. Enriching national donor data after donation could allow for tailored donor follow-up.

Lost wages and unpaid time off (affecting nearly 20% of this sample) should be addressed. Donor reimbursement programs might consider the direction of the National Bone Marrow Program, which covers donor-associated travel expenses for donors and a companion, regardless of economic status (34). Klarenbach *et al.* quantified donor expenses and recommended cost neutrality options (35), while LaPointe *et al.* suggested ways to financially support donors (36).

Of concern, 38% of our cohort did not feel supported by hospital staff. Donors with postoperative complications felt ignored by both hospital staff and family, similar to other studies reporting that donors "feel forgotten" after donation (3,8,11,16,18,37,38). Our study reinforces on a grander scale the need for improved attention afterward.

One in 20 donors experienced a moderate to extreme financial burden attributable to donation. After donation, 19% took unpaid leave—in effect, a fiscal donation and additional sacrifice on their part. Reimer *et al.* reported that 25% of donors needed to resume work before feeling fully rehabilitated, an observation similar to ours (11). Those with medical or emotional complications, and those with lower education attainment, were more likely to report problems paying household bills because of donation.

Apart from direct and indirect costs, donors find future insurability a stressor (40,41). Yang *et al.* reported that 2%–11% of donors had problems obtaining insurance after donation (17). In our study, some respondents were denied health or life insurance (1.8% and 2.1%, respectively). Given the demographic characteristics of respondents versus nonrespondents, we believe those are an underestimate: More nonrespondents were from groups (younger,

male, and ethnic minorities) that are less likely to have health insurance at donation (42). Additionally, lack of health insurance may impede some from seeking medical or psychological follow-up.

Recipient graft failure was a statistically significant predictor of the composite poor psychosocial outcome, consistent with reports from smaller studies (8). Tong and colleagues' review verified that "the donor's well-being 'depended' on the well-being of the recipient," and feelings of regret, sense of loss, or psychiatric complications were reported when the recipient died or had a poor outcome (43).

Our study provides information on the largest number of donors to date and extends over five decades. However, there are limitations. First, our data are limited to information from three large transplant centers. Second, response rates were less than ideal; differences between respondents and nonrespondents exist. Donors with similar demographic characteristics might not respond at different points in their lives for various reasons; information from previous time points was unavailable for donors who had died. Therefore, response and survival bias are obvious limitations. Third, recall bias is an inherent limitation of any study with this design, and donors might not be accurately recalling items directly related to donation but rather might be thinking of current life circumstances. Fourth, we chose not to test for center effects, in part because we were interested in testing for racial differences and race was somewhat confounded with center. In addition, we had no hypotheses regarding center-level differences on donor outcomes and did not collect center-level data that could be used to explain differences. Finally, only 6% of participants were nonwhite. Participants may not represent regional or national living donor demographics over the same time span because response rates were lower in the nonwhite subgroup.

Our data support the following recommendations to improve psychosocial outcomes for donors:

The hospital should enhance their support of donors, especially those with postoperative complications.

Donor programs should give additional consideration to donors whose recipient's graft has failed, and to those who are unrelated or experiencing emotional difficulty.

Tailored donor follow-up to improve the donor's psychosocial well-being should be studied. The Centers for Medicare & Medicaid Services could incorporate psychosocial/financial status questions into existing follow-up interval surveys (beyond medical follow-up) to determine (and prioritize) areas needing attention.

A donor financial plan addressing income concerns should be confirmed before donation to minimize economic distress postdonation. Further studies should be conducted that deal with promoting cost neutrality.

In conclusion, the RELIVE cohort of donors spanning 50 years indicates that the majority had a positive donation experience. Rating the overall donation experience more negatively was associated with recipient graft failure, donor medical complications or emotional difficulty, and having donated longer ago. Recipient graft failure was the only statistically significant predictor of poor psychosocial

outcome, as defined in this study. In addition, some donors were financially disadvantaged. Enhanced postdonation monitoring and attention to donors at greater psychosocial risk may improve long-term donor outcomes.

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None.

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Supplemental Material

**Interpretation of multivariable linear regression model results presented in Table 3**

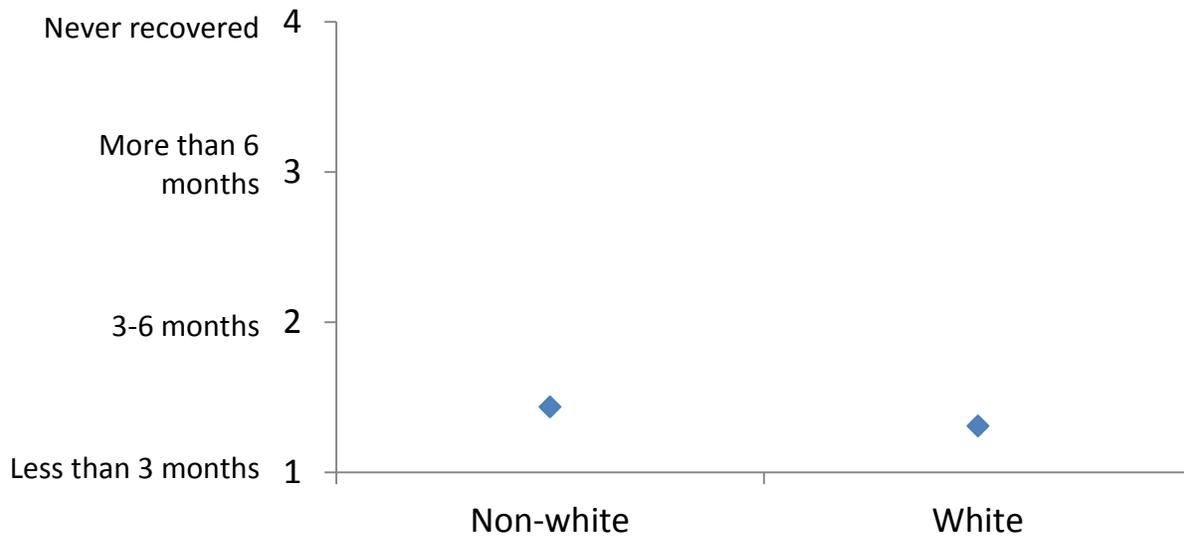
When dichotomous or categorical covariates are modeled as dummy variables, a one-unit difference is the difference between being in the effect group or the reference group. For instance, when we modeled race, white race was the effect group (modeled with the number 1) and non-white race was the reference group (modeled with the number 0). The effects for race, because they are modeled as dummy variables, are therefore interpreted as the difference between white and non-white.

Other covariates were continuous, or measured with multi-point scales and treated as continuous. For example, we examined age and years since donation. Each of these variables was evaluated per 10 years, meaning the regression coefficient of age describes someone who donated at age 30 versus someone who donated at age 40, or likewise a 55-year-old donor versus a 65-year-old donor.

Outcomes of the linear regression models were multi-point scales. For instance, the outcome of overall recovery time was measured as 1 = less than 3 months, 2 = 3 to 6 months, 3 = more than 6 months, and 4 = never recovered. A one-unit increase in this scale would be the difference between any two adjacent categories, such as the difference between 'less than 3 months' and '3 to 6 months.'

Linear regression results are interpreted according to the general formula: Holding  $X_2$  constant, an increase of 1 unit in  $X_1$  is associated with an increase of # in Y. In this scenario, Y is the outcome,  $X_1$  is the effect being interpreted, and  $X_2$  is a covariate that was also included in the model, but is not being interpreted in the sentence. For instance, in the model predicting the outcome (Y) overall recovery time, we included two covariates: race ( $X_1$ ) and surgical procedure ( $X_2$ ). We can interpret the effect of race in this model as: Holding surgical procedure constant, white donors had an overall recovery time that was shorter by 0.13 points than non-white donors. Supplemental Figure 1 shows this association in terms of the mean overall recovery time.

**Figure 1. Mean overall recovery time for non-white and white donors, holding education constant**



The reason we include the phrase “holding surgical procedure constant” in the interpretation is that some white donors and some non-white donors had laparoscopic surgeries, and some white and non-white donors had open surgeries. The model provides the effect of race independent of the effect of laparoscopic surgery. The surgical effect is interpreted as: holding race constant, donors with a laparoscopic surgery had an overall recovery time that was shorter by 0.10 points than donors with an open surgery.

When interpreting 95% confidence intervals, intervals that include 0 are not statistically significant, while intervals that do not include 0 are statistically significant using the criterion  $p < 0.05$ .

Following is a description of mean (average) differences that may help interpretation of the rest of the linear regression results.

- In the model predicting recovery time for daily activities, which was measured on a 4-point scale from “less than 3 months” (1) to “never recovered” (4)...
  - White donors had a recovery time shorter by 0.16 points than non-white donors, holding educational attainment constant. The effect of race indicates that the typical recovery time for daily activities among white donors was 1.08 points (on the 4-point scale), compared to a typical recovery time of 1.24 points among non-white donors.
  - Donors with a graduate degree had a recovery time for daily activities that was shorter by 0.08 points than donors with less than a high school degree (4 units lower on the scale of educational attainment). The typical recovery time for daily activities among donors with less than a high school education was 1.12 points (on the 4-point scale), compared to a typical recovery time of 1.04 points among donors with a graduate degree.
- In the model predicting recovery time compared to expectations, which was measured on a 5-point scale from “much shorter than I expected” (1) to “much longer than I expected” (5)...

- Relative to their expectations, 20-year-old donors reported recovery time of 2.96 points. This 2.96 mean on a 1-5 scale is close to 3, which is the response “about as long” as expected. Typical donors’ reports were relatively stable at 30 years old, 40 years old, and 50 years old (all above 2.90). The age-squared term models the sharper decrease in recovery time compared to expectations for older donors. Sixty-year-old donors reported recovery time relative to expectations of 2.66 points, while 70-year-old donors reported recovery time compared to expectations of 2.35 points. This mean is closer to the response “somewhat shorter” than expected than it is to the response “about as long” as expected.
- Mean recovery time compared to expectations was 2.81 points for male donors compared to 2.96 points for female donors.
- Typical recovery time compared to expectations was 2.99 points for donors with an open procedure compared to 2.72 points for donors with a laparoscopic procedure. (The magnitude of this difference was smaller after adjusting for age and sex.)
- In the model predicting support from friends and family, which was measured on a 5-point scale from “strongly disagree” (1) to “strongly agree” (5)...
  - On average, donors only 10 years out from their donation were close to “strongly agreeing” that family or friends supported them (4.61 points), while individuals who donated 40 years ago were closer to the “agree” response (4.36 points). (The magnitude of this difference was smaller after adjusting for relationship to recipient and emotional complications.)
  - Donors who were related to their recipient reported family and friend support of 4.60 points compared to 4.48 points among donors who were not related to their recipient. (When adjusting for time since donation and emotional complications, the difference between related and unrelated donors was larger, at 0.17 points.)
  - Donors with an emotional, psychological, or substance abuse complication reported family and friend support of 4.21 points compared to 4.60 points among donors without an emotional complication.
- In the model predicting support from health care providers, which was measured on a 5-point scale from “strongly disagree” (1) to “strongly agree” (5)...
  - Twenty-year-old donors reported support from health care providers of 3.41 points, compared to 3.80 points among 60-year-old donors. (The magnitude of this difference was smaller after adjusting for sex, medical complications, and emotional complications.)
  - Men reported support of 3.73 points, compared to 3.57 points among women.
  - Donors with a medical complication reported support from health care providers of 3.34 points compared to 3.70 points among donors without an emotional complication. (The magnitude of this difference was smaller after adjusting for age, sex, and emotional complications.)
  - Donors with an emotional, psychological, or substance abuse complication reported support from health care providers of 2.87 points compared to 3.66 points among donors without an emotional complication. (The magnitude of this difference was smaller after adjusting for age, sex, and medical complications.)

- In the model predicting feeling that no one paid attention, which was measured on a 5-point scale from “strongly disagree” (1) to “strongly agree” (5)...
  - Donors with a medical complication reported more agreement that they felt no one paid attention, with an average of 2.03 points compared to 1.71 points among donors without an emotional complication. (The magnitude of this difference was smaller after adjusting for emotional complications.)
  - Donors with an emotional, psychological, or substance abuse complication reported more agreement that no one paid attention, with an average of 2.48 points compared to 1.74 points among donors without an emotional complication. (The magnitude of this difference was smaller after adjusting for medical complications.)
- In the model predicting feeling closer to the recipient, which was measured on a 5-point scale from “strongly disagree” (1) to “strongly agree” (5)...
  - Twenty-year-old donors reported agreement that they felt closer to their recipient of 3.89 points, compared to 4.20 points among 60-year-old donors.
  - Donors with an emotional, psychological, or substance abuse complication reported agreement that they felt closer to their recipient of 3.47 points compared to 4.04 points among donors without an emotional complication. (The magnitude of this difference was smaller after adjusting for medical complications.)
  - Donors who were unrelated to their recipient and not a friend reported agreement that they felt closer to their recipient of 3.63 points compared to 4.19 points among donors who were a parent of their recipient, 4.16 points among donors who were children of their recipient, 3.92 points among siblings, 4.19 points among spouses, 4.06 points among friends, and 3.92 points among donors with another related relationship. (The magnitude of the effects of being a child, sibling, other relative, or friend of the recipient were larger after adjusting for age and emotional complications.)
- In the model predicting thinking the recipient feels indebted, which was measured on a 5-point scale from “strongly disagree”(1) to “strongly agree” (5)...
  - Donors who were unrelated to their recipient and not a friend reported agreement that their recipient felt indebted of 2.83 points compared to 2.09 points among donors who were a parent of their recipient and 2.43 points among spouses. (The magnitude of the effect of being a parent of the recipient was larger after adjusting for recipient graft function, while the magnitude of the effect of being a spouse of the recipient was smaller.)
  - Donors whose grafts were no longer functioning in the recipient reported agreement that their recipient felt indebted of 2.20 points compared to 2.60 points among donors whose grafts were still functioning.
- In the model predicting thinking the recipient doesn’t show enough gratitude, which was measured on a 5-point scale from “strongly disagree” (1) to “strongly agree” (5)...
  - Twenty-year-old donors reported agreement the recipient doesn’t show enough gratitude of 1.76 points, compared to 1.52 points among 60-year-old donors. (The

- magnitude of the effect of age larger after adjusting for medical complications, emotional complications, and relationship to recipient.)
- Donors with a medical complication reported more agreement that recipient doesn't show enough gratitude, with an average of 1.88 points compared to 1.53 points among donors without an emotional complication. (The magnitude of this difference decreases after adjusting for age, emotional complications, and relationship to recipient.)
  - Donors with an emotional, psychological, or substance abuse complication reported more agreement that recipient doesn't show enough gratitude, with an average of 2.32 points compared to 1.57 points among donors without an emotional complication. (The magnitude of this difference decreases after adjusting for age, medical complications, and relationship to recipient.)
  - Donors who were unrelated to their recipient and not a friend reported more agreement that recipient doesn't show enough gratitude, with an average of 1.74 points compared to 1.50 points among donors who were children of their recipient. (The magnitude of the effect of being a child of the recipient was larger after adjusting for age, medical complications, and emotional complications.)
- In the model predicting the donor's perception of the overall donation experience, which was measured on a 5-point scale from "poor" (1) to "excellent" (5)...
    - On average, donors only 10 years out from their donation rated their overall donation experience as 4.35 points, while individuals who donated 40 years ago rated their experience as 4.14 points. (The magnitude of this difference decreases after adjusting for medical complications, emotional complications, and recipient graft function.)
    - Donors with a medical complication reported a less positive overall donation experience, with an average of 3.89 points compared to 4.44 points among donors without a medical complication. (The magnitude of this difference decreases after adjusting for time since donation, emotional complications, and recipient graft function.)
    - Donors with an emotional, psychological, or substance abuse complication reported a less positive overall donation experience, with an average of 3.29 points compared to 4.38 points among donors without an emotional complication. (The magnitude of this difference decreases after adjusting for time since donation, medical complications, and recipient graft function relationship to recipient.)
    - Donors whose grafts were no longer functioning in the recipient reported a less positive overall donation experience, at 4.25 points compared to 4.42 points among donors whose grafts were still functioning. (The magnitude of this difference decreases after adjusting for time since donation, medical complications, and emotional complications.)
  - In the model predicting willingness to donate again, if possible, which was measured on a 5-point scale from "definitely not" (1) to "definitely yes" (5)...
    - On average, donors only 10 years out from their donation were more willing to donate again, rating 4.79 points, while individuals who donated 40 years ago rated their experience as 4.70 points. (The magnitude of this difference decreases after adjusting for race, relationship to recipient, medical complications, and emotional complications.)

- White donors were more likely to donate again, at 4.79 points than non-white donors at 4.67 points. (The magnitude of this difference was larger after adjusting for time since donation, relationship to recipient, medical complications, and emotional complications.)
- Donors who were related to their recipient were more likely to donate again, at 4.79 points compared to 4.72 points among donors who were not related to their recipient. (When adjusting for time since donation, race, medical complications, and emotional complications, the difference between related and unrelated donors was larger.)
- Donors with a medical complication were less likely to donate again, rating this as an average of 4.69 points compared to 4.81 points among donors without a medical complication. (The magnitude of this difference was larger after adjusting for time since donation, race, relationship to recipient, and emotional complications.)
- Donors with an emotional, psychological, or substance abuse complication were less likely to be willing to donate again, with an average of 4.33 points compared to 4.81 points among donors without an emotional complication. (The magnitude of this difference was weaker after adjusting for time since donation, race, relationship to recipient, and medical complications.)
- In the model predicting financial burden, which was measured on a 5-point scale from “no burden” (1) to “extreme burden” (5)...
  - Twenty-year-old donors reported greater financial burden, at 1.39 points, compared to 1.21 points among 60-year-old donors. (The magnitude of this difference was smaller after adjusting for education, medical complications, and emotional complications.)
  - Donors with less than a high school education reported a greater financial burden, of 1.41 points, compared to 1.20 points among donors with a graduate degree. (The magnitude of this difference was smaller after adjusting for age, medical complications, and emotional complications.)
  - Donors with a medical complication reported greater financial burden, rating this as an average of 1.48 points compared to 1.26 points among donors without a medical complication. (The magnitude of this difference was larger after adjusting for age, education, and emotional complications.)
  - Donors with an emotional, psychological, or substance abuse complication reported greater financial burden, rating this with an average of 1.98 points compared to 1.27 points among donors without an emotional complication. (The magnitude of this difference was weaker after adjusting for age, education, and medical complications.)

## Supplemental Material

**eFigure 1. Enrollment Flow Diagram**

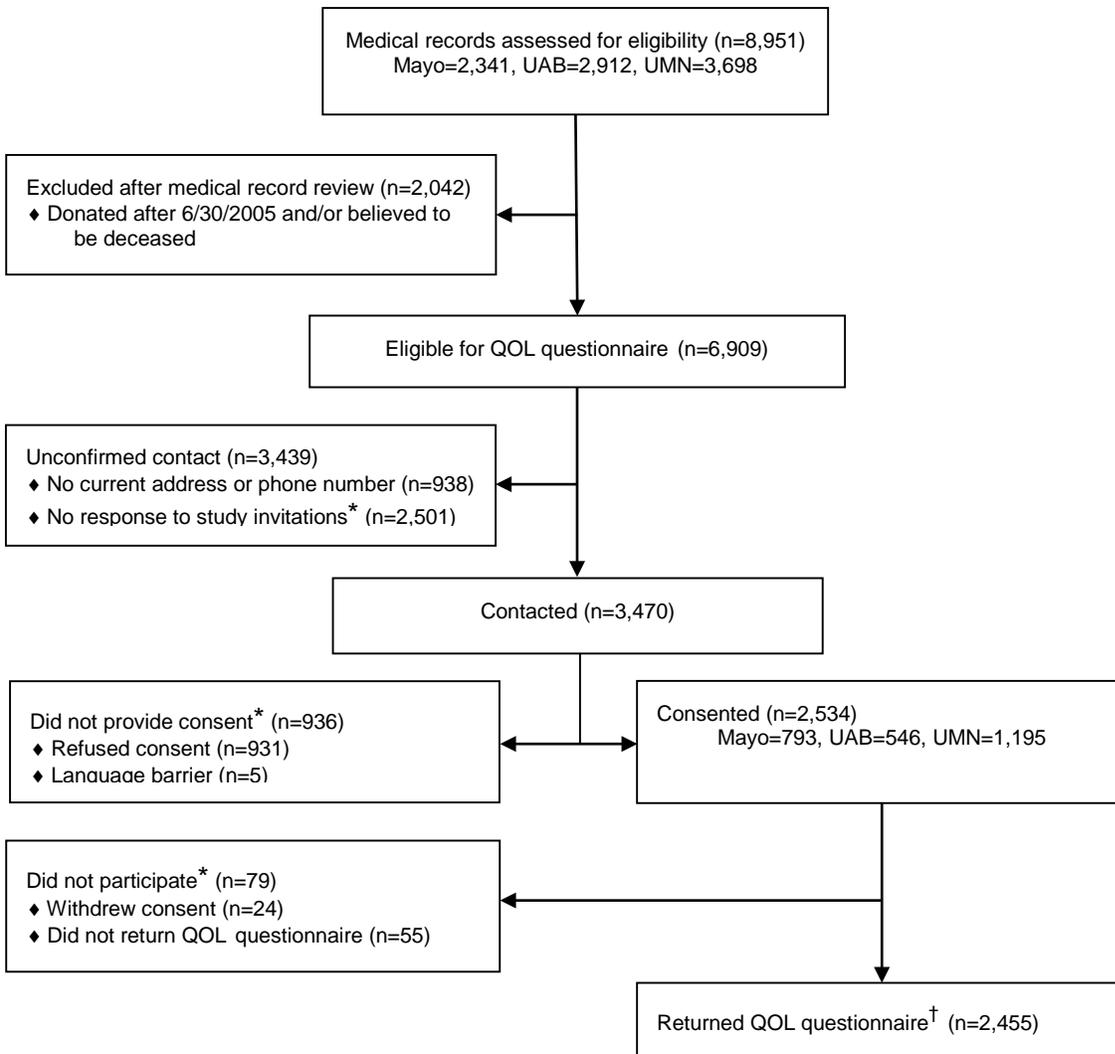
**eFigure 2. Attitudes and Feelings Toward Donation**

**eFigure 3. Donation Experience**

**eFigure 4. Recipient and Donor Outcomes**

**eAppendix. Donor Questions on the QoL Questionnaire**

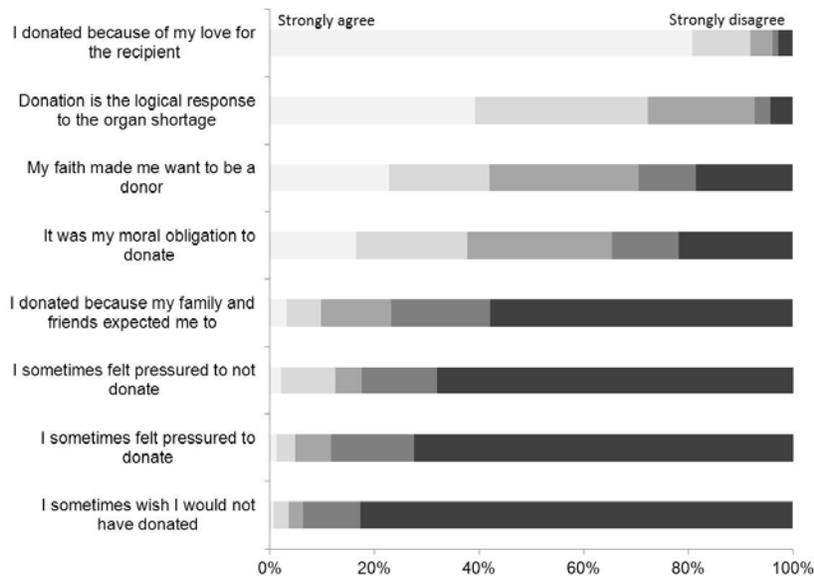
**eFigure 1. Enrollment Flow Diagram. Non-participants (\*, n=3516) and participants (†, n=2455) were tested for comparability of characteristics (see text).**



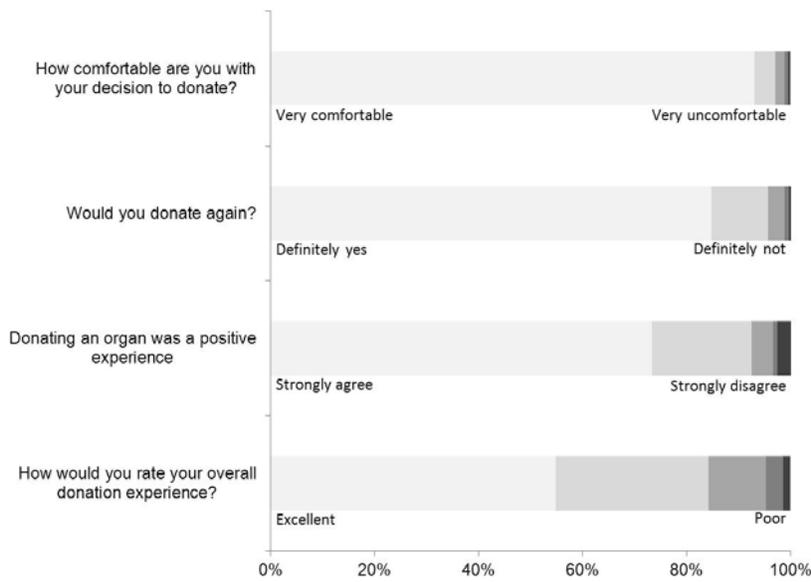
## Donor Participation

Using logistic regression, living kidney donors who were eligible to participate in the QOL study but who did not because they did not respond to study invitations, did not provide consent, withdrew consent, or did not return the QOL questionnaire (n=3,516) had lower educational attainment at donation ( $p < 0.0001$ ) and were younger at donation ( $p < 0.0001$ ) compared to donors who completed the QOL questionnaire (n=2,455). In addition, donors who did not participate in the QOL study were more likely than participants to be black or African American ( $p < 0.0001$ ), male ( $p = 0.0003$ ), and related to their recipient ( $p < 0.0001$ ). Figure previously published in Gross et al., Health-Related Quality of Life in Kidney Donors from the Last Five Decades: Results from the RELIVE Study. 2013; 13: 2924-2934.

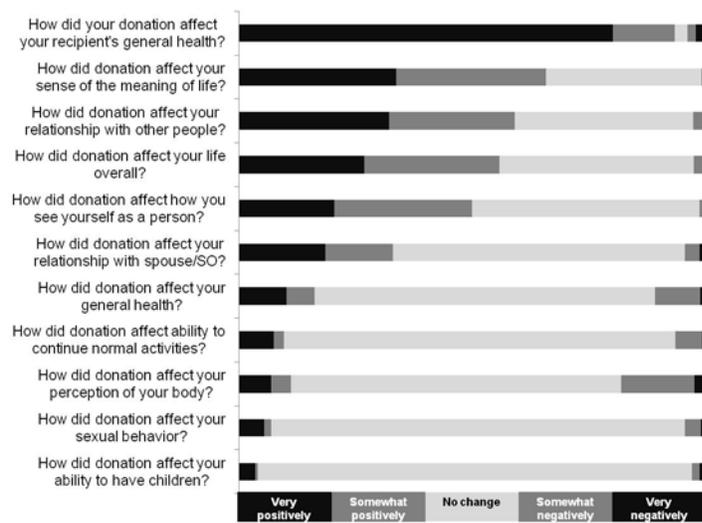
**eFigure 2. Attitudes and Feelings Toward Donation**



**eFigure 3. Donation Experience**



**eFigure 4. Recipient and Donor Outcomes**



Note that the color density scale becomes darker as answers become more extreme to emphasize the category “no change.”

## **eAppendix**

### **Donor Questions on the QoL Questionnaire**

#### DONATION EXPERIENCE

17. How would you rate your overall organ donation experience? (Mark one response.)

Excellent  Very Good  Good  Fair  Poor

18. Which of the following best represents the reason you volunteered to be a living donor?

I was asked by my recipient

I was asked by someone other than my recipient

I volunteered to donate on my own

19. Thinking about the length of time for recovering after surgery, which one of the following statements best describes your recovery time?

Much longer than I expected

Somewhat longer than I expected

About as long as I expected

Somewhat shorter than I expected

Much shorter than I expected

20. How much time did it take for you to recover from surgery?

Less than 3 months

3 to 6 months

More than 6 months

Never recovered

21. How long after donation surgery did it take you to return to your usual daily activities, such as walking, driving a car, or shopping for groceries?

Less than 3 months

3 to 6 months

More than 6 months

I never returned to my usual daily activities

22. Please answer these questions about your experience after your donor surgery.

Did you have any medical complications that resulted in additional hospitalization days or re-hospitalization after your donor surgery?  Yes  No

Did you have any medical complications that did not require hospitalization after your donor surgery?  Yes  No

Are you currently seeing a doctor or other health care provider for medical problems related to the donor surgery?  Yes  No

Did you have any emotional, psychological, or substance abuse difficulties (e.g., depression, anxiety, mood changes, etc.) that were the result of your donation?  Yes  No

Did you obtain professional help (e.g., counseling, medication, etc.) for emotional, psychological, or substance abuse concerns that were a result of your donation?  Yes  No

*If yes* Are you currently receiving treatment for this problem?  Yes  No

23. If you marked "Yes" to any of the questions above, please provide a description of your experience(s) in the space provided below.

24. Before your donation, had you ever been treated for emotional, psychological, or substance abuse difficulties?  Yes  No

If yes, please provide a description of your experience(s) in the space provided.

25. Have you had any of the following problems because of donation? (Mark one response per line.)

I was denied health insurance because of donation  Yes  No  Don't know

My health insurance premium increased because of donation  Yes  No  Don't know

I was denied life insurance because of donation  Yes  No  Don't know

My life insurance premium increased because of donation  Yes  No  Don't know

I had problems paying household/routine monthly bills because of donation  Yes  No  Don't know

I had problems paying medical bills because of donation  Yes  No  Don't know

I took unpaid medical leave from work because of donation  Yes  No  Don't know

26. Do you feel that donating your kidney caused a financial burden for you?

No burden  Little  Moderate  Great  Extreme burden

27. If you could do it over again, would you donate again?

Definitely yes  Probably yes  Not sure  Probably not  Definitely not

#### ATTITUDES ABOUT DONATION

28. The following questions involve your feelings about donating. How much do you agree or disagree with each of the following statements?

I sometimes wish I would not have donated  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

I sometimes felt pressured to NOT donate  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

Overall, donating an organ was a positive experience in my life  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

I donated because of my love for the recipient  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

I donated because my family and friends expected me to  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

My faith made me want to be a donor  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

It was my moral obligation to donate  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

Donation is the logical response to the organ shortage  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

I sometimes felt pressured to donate  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

29. Below are some of the ways people feel after donating. How much do you agree or disagree with each of the following statements?

I felt depressed for a while after the surgery  Strongly agree  Agree  Unsure  Disagree  Strongly disagree

Once the surgery was over, no one really paid much attention to me  Strongly agree  Agree  Unsure  Disagree  Strongly disagree

There was a lot of support available to me after the surgery from the health care providers  Strongly agree  Agree  Unsure  Disagree  Strongly disagree

My family or friends supported me throughout the donor surgery  Strongly agree  Agree  Unsure  Disagree  Strongly disagree

30. On a scale of 1 to 10 where 1 is “Not at all informed” and 10 is “Extremely informed,” how well informed do you feel now about organ donation?  1 Not at all informed  2  3  4  5  6  7  8  9  10 Extremely informed

31. How comfortable are you now with your decision to donate? Would you say you are:

- Very comfortable with the decision
- Somewhat comfortable with the decision
- Neutral
- Somewhat uncomfortable with the decision
- Very uncomfortable with the decision

32. How did your donation affect the following areas of your life?

Your general health  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your perception of what your body looks like  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your sexual behavior  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your ability to have children  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your ability to continue the normal activities you did before the donation  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

How you see yourself as a person  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your sense of the meaning of life and what is important to you  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your relationship with your spouse or significant other  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your relationship with other people involved in the donation  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your life overall  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

#### DONATION-RELATED RELATIONSHIPS

33. Is the recipient you donated to still alive?

- Yes  No  Don't know/not applicable

*If yes* How much do you agree or disagree with the following statements?

Since I donated, I feel closer to the recipient  Strongly agree  Agree  Unsure  Disagree  Strongly disagree

Sometimes I think the recipient feels like he/she is in debt to me  Strongly agree  Agree  Unsure  Disagree  Strongly disagree

I sometimes feel like the recipient does not show me enough gratitude  Strongly agree  Agree  Unsure  Disagree  Strongly disagree

34. How did your donation affect your recipient's general health?

- Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively
- Don't know/not applicable

35. How did your donation affect your relationship with the recipient?

- Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively
- Don't know/not applicable

36. Is the organ you donated still functioning in the recipient?

- Yes  Yes, but with current problems with function  No  Don't know/not applicable

37. Did the person who received your donated organ have medical complications after their surgery?

- Yes
- No
- Don't know/not applicable

*If yes* How severe were their complications?

- Mild  Moderate  Severe  Very severe

#### ABOUT YOU

38. What is the highest grade or level of school you have completed?

- 8<sup>th</sup> grade or less
- Some high school
- High school graduate or GED
- Vocational, Technical, or Business School
- Some college or Associates Degree (including Community College)
- Four year college graduate (Bachelor's Degree)
- Graduate or Professional School
- Other, specify:

39. Are you currently...

- Married  Living with someone in a marriage-like relationship  Separated  Divorced  Widowed  Never been married

40. Were you working for pay at the time of donation?

- Yes  No – Skip to question 41

If yes, please rate how supportive your employer was of organ donation by marking the box that best describes the level of support.

- Not very supportive
- Not supportive
- Neutral or unsure
- Supportive
- Very supportive

If you were working at the time of donation, how much time elapsed after surgery before you were able to return to your pre-donation work status?

- Less than 1 week  1 to 2 weeks  3 to 4 weeks  5 to 6 weeks  More than 6 weeks  Unable to return to work due to complications from donation  Did not return to work by choice

41. Which of the following best describes you now?

- Working full-time for pay (35 or more hours a week)
- Working part-time for pay

Not working for pay at present → Are you... (Mark all that apply.)

- A full time homemaker
- A seasonal worker
- Looking for a job
- Retired
- In school
- None of the above

42. Are you Hispanic or Latino?

- Yes
- No
- Not sure/Don't know

43. Which of the following best describes you?

- White or Caucasian
- Black or African American
- American Indian or Alaskan Native
- Asian or Pacific Islander
- Something else? Describe:

44. Do you have any life insurance coverage?

- Yes  No

45. Are you CURRENTLY covered by any of the following types of health insurance or health coverage plans?

Insurance through a current or former employer or union (yours or another family member)   
Yes  No

Insurance purchased directly from an insurance company (yours or another family member)   
Yes  No

Medicare, for people age 65 and over, or people with certain disabilities  Yes  No

Medicaid, Medical Assistance, or any kind of government-assistance plan for those with low incomes or a disability  Yes  No

TRICARE or other military health care  Yes  No

VA (including those who have ever enrolled for or used VA health care)  Yes  No

Indian Health Services  Yes  No

Any other health insurance or health coverage plan, please specify:

46. Did someone help you complete this survey?

- Yes  No

*If yes* How did that person help you?

- Read the questions to you
- Wrote down the answers you gave
- Answered the questions for you
- Translated the questions into your language

47. Do you have further comments about organ donation?

# **Emotional and Financial Experiences of Kidney Donors over the past 50 Years: the RELIVE Study**

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